The Challenge of Breast Cancer
A brochure to accompany the information film for women with early and advanced breast cancer
Breast cancer is a diagnosis that evokes a sense of fear, helplessness and perplexity. It strikes directly at the heart of the affected individual as well as her family and friends. It is important to know that for an ever-increasing number of women today: breast cancer can be cured. This brochure is intended to help women with breast cancer become familiar with the illness and feel more assured by being thoroughly informed. Women who are facing a recurrence of breast cancer will also find important assistance. Therefore, in addition to therapeutic options for early stages of breast cancer, this brochure will also provide information about methods used to treat advanced breast cancer.

Besides providing medical information, it is just as important to help the affected individual deal with her personal response to the illness. For this reason, she will also find answers to questions that relate to the social and psychological aspects of the diagnosis of breast cancer, one that is often experienced as life-threatening: How should I relate to my environment, my partner, my friends? To whom can I turn if I am concerned about caring for my children? What will be of real help to me in this difficult situation? How can I deal with the experience of my own mortality?

In association with the film “Through my breast into my heart – the challenge of breast cancer”, this brochure will once again present the most important facts about the illness, supplemented with helpful information. This way, patients need not feel left alone with their diagnosis. The hope, instead, is to give them the opportunity to actively participate in designing their own healing process, by taking an active role in dealing with the illness.

Breast cancer – not a rarity
Every year, about 72,000 women develop breast cancer in Germany; that is, on average, one out of every eight women will be affected by breast cancer during her lifetime. Men can also suffer from breast cancer, but with 230 to 500 cases per year in Germany, they represent a small group when compared to female patients with breast cancer.
How breast cancer develops

We do not as yet fully understand why some women develop breast cancer and others do not. However, there are specific risk factors that promote the occurrence of breast cancer. These may be classified into non-modifiable factors – that is, genetic risk factors – and modifiable factors – such as environmental factors, life habits, childbearing patterns and hormonal influences.

Genetic factors
Only between 5 and 10 per cent of patients with breast cancer have an inherited or inheritable risk factor for breast cancer. To date, we know of two genes where mutations result in a high risk of developing breast or ovarian cancer: BRCA 1 and BRCA 2, (short for “breast cancer gene”). If first-degree relatives (mother, daughter or sister) have had breast cancer or ovarian cancer, the chances are greater that there is genetic loading. Therefore, genetic testing is recommended if any of the following constellations is found in either paternal or maternal relatives:

- three women with breast cancer regardless of age
- two women with breast cancer, one of them with illness occurring prior to age 51
- one woman with breast cancer and one woman with ovarian cancer
- two women with ovarian cancer
- one woman and one man with breast cancer
- one woman with ovarian cancer and one man with breast cancer
- one woman with breast cancer occurring prior to age 36
- one woman with bilateral breast cancer whose illness began prior to age 51
- one woman with both breast and ovarian cancer.

Patients who have previously had breast cancer are at higher risk of developing cancer in the other breast compared to healthy women. In addition, it is important to note that genetic abnormalities are seen more frequently in certain ethnic groups.

The Centre for Familial Breast and Ovarian Cancer provides specific counselling for women who are concerned about a possible genetic risk for breast cancer at twelve offices in federally sponsored clinics throughout Germany. The consultations include obtaining a genetic history (family history of illnesses) and a genetic analysis, and in addition offer comprehensive counselling so that affected women can fully understand the implications of genetic testing.

Affected women should ask their doctor whether genetic testing would make sense in their family. Typically, such testing is covered by statutory health insurance. It is always advisable to obtain individual counselling and intensive follow-up examinations if there is genetic loading. Since breast cancer centres are specifically designed to provide specialised care of this kind, they are also able to provide the best possible care for women who are suffering from recurrent or relapsed breast cancer.

In addition, all women have the opportunity to participate in a standardised early detection programme. Experts in breast diseases from different specialist fields, together with ‘breast care nurses,’ i.e. nursing specialists in breast diseases, can provide optimal care both during and after the illness.

Reproductive behaviour
Pregnancy and birth history is also considered a risk factor for the development of breast cancer. The longer a woman is exposed to the cyclical alterations in oestrogen and progesterone levels (female sex hormones), the higher the likelihood that she develops breast cancer. For this reason, the following circumstances are considered risk factors:

- Periods beginning prior to age 13 (Early menarche)
- Menopause after age 52 (Late menopause)
- Childlessness or advanced age at the time of the first birth (older than 30 years)
- No breast feeding or only brief periods of breast feeding.
A breast lump may have many causes, most of them harmless. Any collection of cells — whether benign or malignant — is referred to as a tumour. However, we only use the term ‘breast cancer’ to refer to a malignant tumour; this is the most common form of cancer in women, and is also known as mammary carcinoma. Breast cancer arises when cells in the breast degenerate and begin to grow unchecked, that is, reproduce continuously. The two commonest kinds of breast cancer originate from the cells of the milk ducts (ductal mammary carcinoma, 70 to 80 per cent) and the milk glands (lobular mammary carcinoma, 10 to 15 per cent). Evolution from a single degenerated cell to a palpable lump can take years. For this reason, although the diagnosis of breast cancer must be taken extremely seriously, it does not represent a medical emergency. This is also true in the case of a recurrence of breast cancer.

What is breast cancer? When is a lump malignant?

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Hormonal influences
Sex hormones also appear to play a not insignificant role in the development of breast cancer. There are contradictory studies regarding the effect of hormonal treatments such as the birth control pill or oestrogens and progestational agents during menopause. It is possible that the long-term use of birth control pills may have an unfavourable effect on breast cancer risk, even though the increase of this effect would appear to be rather small and it may be statistically offset by the protection from other forms of cancer provided by hormonal contraception.

According to the results of the latest research, hormone replacement therapy during menopause definitely increases the risk of developing breast cancer. Professionals are also concerned about ingestion of botanical preparations that contain what are known as phytohormones. The risk potential for many substances is probably greater if they are taken for longer time periods. Especially for women during and after menopause, the use of these substances is not without risk.

Life habits and environmental factors
In addition, smoking, overweight, excessive alcohol consumption and diabetes mellitus increase the risk of developing breast cancer. A poor diet may play a significant part if it is excessive in animal fats or deficient in certain vitamins and minerals or in dietary fibre from fruits and vegetables. Environmental pollution has been insufficiently researched to date to be included as a risk factor.

Prof. Dr. med. Ulrike Nitz
“We do not know where this disease comes from. Clearly, life circumstances in the Western world constitute one problem. Ultimately, breast cancer occurs significantly more frequently here.”

Tumour growth begins with the degeneration of cells in the milk ducts or the glandular tissue of the breast. This early stage — referred to as ‘carcinoma in situ’ — can be recognised on mammography and typically cured through surgery. The rate at which the cancer evolves depends upon many factors, among them whether and how strongly the tumour cells respond to hormones or other messenger substances as growth stimulants.
“During my screening, they found a very tiny carcinoma measuring seven millimetres in my left breast. I said to the lady: That’s not possible. It can’t be happening to me. I always thought nothing like this could ever happen to me.”

Cyst, benign tumour or cancer?

A cyst or benign tumour is typically well demarcated from the surrounding breast tissue and thus easily movable. A lump is suspicious if it is poorly demarcated and also hard to move around. So the most frequent sign of breast cancer is a painless (that is, not sensitive to pressure) lump arising in the glandular breast tissue on one side, which typically feels bumpy and rough to the touch.

If the tumour is growing in the tissues directly under the skin, skin changes are usually detectable. In this case, the skin or the nipple may be permanently puckered over the tumour. The breast may appear red and may be weepy. However, a relatively harmless infection may also cause similar symptoms. Fluid discharge from the nipple, especially if it is bloody or like mucus, may also suggest the presence of cancer.

Additional symptoms of breast cancer arise if it has spread through metastases. In nearly all cases, the first areas that are involved outside the breast are the lymph nodes in the axillae (armpits). Enlarged lymph nodes that are affected by tumour can be palpated as rough lumps in the armpit, which sometimes grow together. For the affected individual it is often hard to distinguish between lymph nodes enlarged from inflammation (e.g. due to an ordinary infection) and a lymph node affected by cancer.

Over its further course, breast cancer may go on to spread to different organs. It frequently spreads to the bones, especially the spine or the pelvic bones, and to the bone marrow, lungs, liver and the brain. Most secondary tumours are either discovered in the course of follow-up care or by the affected woman herself, who may feel a new lump in her breast or note the occurrence of other symptoms.
Prevention and early detection

Along with regular visits to the doctor, breast self-examination still remains the best method of early detection. Women themselves discover more than 30 percent of tumours. In addition, a baseline mammography examination should be performed at age 40 to serve as a comparison for later X-ray examinations.

Beginning at age 50, the recommendation is that mammography should be performed at a certified facility every two years as a routine preventive test. If breast cancer was already diagnosed at an earlier point, medical examinations will take place at more frequent intervals. Here, you should follow the advice of your own doctor.

Additionally, every woman should perform a monthly breast self-examination, preferably just after her monthly period when the breast is relaxed. Since the glandular tissue may normally feel slightly lumpy, palpation may sometimes be difficult. It is easier to examine the breast if it is oiled.

Instructions for self-examination

To perform breast self-examination, the woman should stand before a mirror with good illumination and inspect the shape and appearance of the breast skin and the nipples. An unchanged difference in size between the two breasts is normal. With arms elevated, both breasts should be inspected from the front and the side and examined for any abnormalities.

Palpation is best done with the three middle fingers extended along the breast. One should begin in the upper outer quadrant (most women have denser breast tissue in this area) and then proceed counter clockwise to cover first one and then the other breast. Next, each nipple should be squeezed between the thumb and forefinger and examined to see if any fluid emerges.

Next, the entire examination should be repeated while lying down. Finally, the axillae should be examined to detect possibly enlarged or hardened lymph nodes.

What should I look for when palpating my breast?
- Is the breast tissue similarly moveable against the skin in all areas?
- Is the tissue hardened in any places?
- Is the breast tender anywhere?
- Can you detect any redness or inflammation?
- Are there any skin areas that are retracted or prominent?

Prof. Dr. med. Ulrike Nitz
“Early on, we have the possibility of establishing a very good risk profile. Does this tumour have a major tendency to spread? How large is the tumour? All of this information is available to us relatively early on, so that we can begin the race very well informed.”
Local diagnosis
The diagnosis of breast cancer involves several steps, and among these the most important investigative methods are palpation, mammography, ultrasound examination and a tissue examination (biopsy). Not every lump means cancer. However, it is important that a gynaecologist clarify every palpable lump. The type of procedure that is used depends upon many factors, including the density of the glandular tissue.

Findings on palpation
Between 70 and 80 per cent of tumours visible on mammography can also be detected by palpation. Thus, palpation is the simplest and most effective method for discovering a lump. Every woman can perform this examination herself – as described.

Mammography
Mammography is an X-ray examination that involves taking a series of X-ray images of the breast in different positions. Specific signs on mammography that point to breast cancer are star-shaped shadows or very small clustered calcifications referred to as 'microcalcifications'. These develop because cancer-damaged cells, unlike normal breast tissue, accumulate calcium, which appears white on the X-ray image. The predictive value of mammography depends on the density of the breast tissue. For this reason, other methods may be used, especially in younger women with dense glandular tissue. Thanks to modern technology, the radiation burden from mammography is small.

Ultrasound
This method is used as a supplement to mammography and provides the physician with additional help in determining whether a lump is benign or malignant.

Biopsy
If palpation, mammography and possibly an ultrasound examination have led to serious suspicion that a lump is malignant, a tissue sample needs to be taken from the breast to be microscopically analysed for the presence of cancerous cells. This precise laboratory tissue diagnosis provides a reliable diagnosis. In many cases it is possible to obtain breast tissue without the need for an operation, but sometimes a surgical biopsy is more advantageous.

There are three different kinds of biopsy: in an ultrasound-guided punch biopsy, suspicious tissue is simply removed from the breast using a hollow needle. By contrast, a vacuum biopsy is computer guided and allows for the very accurate removal of a larger amount of tissue. If a punch or a vacuum biopsy does not provide sufficient clarity, then the entire area under suspicion is removed by means of an open biopsy. The removed tissue is then examined for the presence of degenerated cells. If cancer cells are found, the tissue that has been removed (now termed a tumour) is additionally examined to determine its specific characteristics. These tumour characteristics are important for making subsequent treatment decisions.

Tumour markers
This blood test looks for the presence of specific proteins sometimes produced by breast cancer cells, known as tumour markers. Tumour marker CA 15-3 is relatively specific for breast cancer. However, simply the presence of this marker does not allow us to make a diagnosis, but during and after treatment it can help evaluate the course of the disease.

Prof. Dr. med. Nadia Harbeck
“Today, we can cure 70 to 80 out of every 100 women who present with primary disease. The problem is that we cannot promise each individual patient a cure.”
Determining the spread of tumour in the body
Once the diagnosis of breast cancer has been established, further tests are conducted to reveal whether the cancer has spread to involve other organs, that is, whether it has already formed metastases.

X-rays and computer tomography (CT)
X-ray examination of the chest can help detect involvement of the lymph nodes or the lungs. Metastases are only detectable once they have grown to a certain size. If necessary, computer tomography provides more precise information. In this procedure, multiple X-ray images are taken in succession, for example, of the thorax, and the doctor can examine these images in layers.

Bone scans
To determine whether the bony skeleton has been affected by breast cancer, a bone scan is performed. In this test, the patient is injected with a radionuclide, technetium-99m phosphate – a molecule that specifically accumulates in bone. The radiologist uses a specialised camera to examine the entire bony skeleton for areas that have absorbed the radionuclide. Those portions of bone with active tumour take up more radionuclide and can thus be distinguished from the rest of the skeleton.

Magnetic resonance tomography - MRI
The MRI is performed in a similar way as computer tomography, but instead of using X-rays it uses fluctuating magnetic fields. However, MRI is only used in specific situations.

Should there be suspicion of metastases or a local recurrence, the same diagnostic tests will be performed as were used for the initial diagnosis. Thus, not all of the examination methods will be performed on every patient – the process of diagnosis is individually determined for each patient.

“I said from the very beginning, it’s not going to destroy me. I will die at some point, but cancer can’t kill me yet.”
Stage classification of breast cancer

The prognosis and treatment of breast cancer are dependent on the stage of the illness.

Early stages
Stage 0: No infiltrating (destructive) growth of the cancer has occurred yet (Carcinoma in situ = pre-cancerous stage).
Stage I: Is defined as infiltrating carcinoma that is less than two centimetres in size – at this stage, the breast cancer is limited to the breast itself.

Advanced stages
Stage II: The cancer is between two and five centimetres in size. There is often early spread into the first (sentinel) lymph nodes.
Stage III: Is defined by spread of the carcinoma to the lymph nodes.

Metastasised stage
Stage IV: The cancer has spread to other organ systems.

Inflammatory breast cancer
Inflammatory breast cancer is a rare form of the disease. The breast looks inflamed because it is red and hot. The skin can have ridges or dimpling or can appear pitted. Inflammatory breast cancer tends to spread rapidly.

Recurrence
Recurrence means a relapse, that is, the cancer has returned after treatment – either limited to the breast (local recurrence) or in distant sites (metastasised).

The TNMG Classification is a staging system that is used for many malignant diseases.

In this system, T stands for tumour size, N stands for lymph node status, M stands for the presence or absence of metastases, and G stands for the histological grade of differentiation (that is, how much the tumour cells deviate from normal cell structure).

As long as the tumours have not extended beyond the limits of the organ, one speaks of an early stage of breast cancer. When the tumour has reached a critical size, the cancer cells begin to spread into the surrounding breast tissue through lymphatic channels.
The question, “Why did this have to happen to me?” often leaves women at an emotional impasse. It reflects the sense of powerlessness that comes along with the diagnosis. “Am I responsible for my illness? Or maybe it’s the fault of global environmental pollution?” Patients ask such questions because they are seeking an active engagement with their illness. Today, we know that neither the occurrence of breast cancer in general nor the development of metastases has anything to do with one’s personality or inappropriate behaviour and that breast cancer has a variety of possible causes.

The nature of a patient’s prognosis in the case of recurrence depends on a number of factors. In addition to the TNM classification, other characteristics also play a part. Apart from the doubling time of the tumour (the time it takes for it to grow twice as large) and its tendency to form metastases, the degree of malignancy is also determined by the biological composition of the tumour, that is, whether it is positive for hormone receptors or for HER2/neu, (more about this topic in the chapter “antibody therapy”). Thus, the classic prognostic factors are:

- Tumour size
- Lymph node status
- Presence of metastases
- Grading (Deviation of the malignant cells from normal cell structure)
- Hormone receptor status
- HER2/neu receptor status
- Age

It is essential to come to an acceptance of the diagnosis and to learn to cope with it. In this process, it is advisable to accept assistance and to explore what feels helpful for one’s own healing process.

Very important for the next steps:
The diagnosis of breast cancer - including a recurrence – is not an acute emergency. There is time to seek a second medical opinion and to calmly consider the right place to secure optimal treatment.

To determine the most optimal treatment – whether for the initial illness or a recurrence - it is necessary to first perform a number of additional tests to find out precisely how widespread the cancer is. The more accurate the determination of the stage, the better one can plan subsequent treatment. Treatments for breast cancer must be adapted to the stage. That is, only when the exact stage has been established through the investigatory methods that have been named previously can the therapeutic steps be set out.

When local recurrence or metastases are suspected, then in principle, the same range of therapeutic measures is used as for the initial diagnosis.

After a tissue biopsy, determination of the size and extent of spread of the tumour along with its specific tumour characteristics, an individual treatment plan is developed for each patient. In this situation, the patient has sufficient time to calmly think about which therapy would be right for her. If she is uncertain, she can seek a second opinion and obtain advice from other experts. In addition, it may be helpful for her to consult a psycho-oncologist or to speak with other breast cancer patients about their experiences.

Early stage
The following treatment options are available for early stage breast cancer after surgical removal of the tumour: chemotherapy, radiotherapy, anti-hormonal treatment and antibody therapy. The type of treatments that will be used and whether they are used in combination depends on various factors. First and foremost, these include the size and extent of the tumour along with its specific characteristics. The same considerations apply in the case of a local recurrence. If the location of the tumour permits, it will be completely removed surgically. In order to prevent a tumour from recurring at the same site, the area will also be irradiated.

Prof. Dr. med. Ulrike Nitz
“Of all the forms of malignancy we know, breast cancer is one of the most thoroughly studied today. This know-how is concentrated at the breast centres. All specialities important to the treatment of breast cancer are represented there.”
However, we can only perform additional radiation therapy if there is still a “radiation reserve”, that is, if this area of the body can tolerate additional irradiation. The maximum allowable radiation dose is limited to a specific amount based on the specific nature of different tissue structures.

**Advanced stage**
In the advanced stage of breast cancer as well, the first step is surgical intervention. The next step is most often chemotherapy, which may be combined if necessary with radiation therapy, anti-hormone therapy, antibody therapy, or what are known as small molecules. Whereas a local recurrence is often treated by surgery and/or radiation alone, systemic therapy (antibodies and/or chemotherapy, antihormonal therapy) is generally required if distant metastases have already developed. In any case, it is important to include effective pain therapy in the treatment plan from the very beginning.

**Metastasised stage**
A cure currently cannot be achieved in the metastatic stage. Yet, by employing modern therapeutic modalities, such as antibody therapy, angiogenesis inhibitors and small molecules, breast cancer can often be controlled for long periods – and we can speak of turning the disease into a chronic illness (with a long-term course). Various medications can be used successively in order to halt tumour growth with a new substance each time. In addition, during this stage, the goal is to try to apply therapeutic measures gently in order to maintain a sustained and stable quality of life for the patient.

**Don’t panic!**
It generally takes a few days – at most a week – to establish a firm diagnosis. And it often takes a few more days to select a hospital and to arrange for the necessary appointments. Take time to inform yourself thoroughly, to arrive at your decisions calmly and to seek appropriate support.

Clinical studies offer you the option of using newly developed forms of treatment. Studies test new medications, specific therapeutic measures and medical interventions with regard to their effectiveness and safety. The patient is never a “guinea pig” in such studies – there are adequate safety data available at this point. Moreover, as a rule, in clinical studies the new medication is administered in addition to standard customary therapy.

“The fundamental principle is:
Every woman has the right to refuse a particular treatment or to withdraw her previous consent to treatment.
**Current surgical treatment models**
The initial treatment of a tumour diagnosed as malignant is to remove it surgically. The amount of breast tissue that must be removed during the surgery depends upon the size and location of the tumour. It has been shown that radical surgery has no impact on long-term prognosis; that is, there is no reason to remove any more tissue than necessary. The successful result of this knowledge is that today, almost 80 per cent of mammary carcinoma can be treated with breast-sparing surgery, and the hope is that in the future, it will be possible to increase this figure by an additional five to ten per cent.

**Breast-sparing (breast-conserving) surgery**
In breast-sparing surgery, the entire tumour is removed along with a margin of healthy tissue surrounding the tumour – if at all possible, one centimetre on all sides. This border area around the tumour acts as a safety margin between the healthy and diseased tissues. A major criterion for breast-sparing surgery is the ratio of breast size to tumour size. Thus, a larger breast may not need to be removed even for a tumour measuring five centimetres in size, as long as the tumour can be removed with a surrounding margin of one centimetre of healthy tissue. From a cosmetic perspective, breast-conserving surgery is the ideal solution: only a small, scarcely visible scar remains. The operative incision is usually made directly over the tumour tissue. Along with surgery on the tumour, until recently the practice was to also remove all of the lymph nodes in the axilla in order to determine the stage of the disease. This may result in unpleasant side effects such as lymphatic stasis, paralysis of the arm or pain with movement.

Newer operative procedures that have by now become standard, including sentinel node biopsy, should help reduce the need for large-scale removal of lymph nodes from the axilla (axillary dissection). The sentinel lymph node is the node anatomically closest to the breast area affected by cancer. It is marked using X-ray contrast medium and deliberately removed during the operation and then carefully examined under the microscope. If the cancer has not invaded the sentinel node, one can assume with a high degree of probability that the remaining lymph nodes are also unaffected. This means that removing additional lymph nodes is not necessary and dramatically reduces the incidence of side effects.

**Depending whether therapy is administered before surgery or after surgery, we distinguish between neoadjuvant and adjuvant therapy.**

**Neoadjuvant therapy**
Neoadjuvant therapy means beginning chemotherapy even before surgical treatment. The aim is that the malignant tumour be made smaller prior to the operation, so that women with a small breast and a large tumour, for example, may still be able to undergo breast-sparing surgery.

**Adjuvant therapy**
Adjuvant therapy takes place after the operation. At this point in time, quite a bit is known about the nature of the tumour: its size, its hormone and HER2/neu receptor status, as well as the presence or absence of lymph node involvement. These factors help determine the type of subsequent therapy – radiotherapy, chemotherapy, antihormonal therapy, antibody therapy – to be administered. The aim is to destroy all cancer cells remaining in the body with the follow-up treatment, in order to prevent a new occurrence or progression of the disease.

In a sentinel node biopsy, only those lymph nodes are removed that are located closest to the tumour, the so-called ‘sentinel nodes. They can be specifically demonstrated using radioactive markers and a blue dye. The remaining lymph nodes that are unaffected are not removed. This makes it possible to significantly decrease side effects.

**Dr. med. Andrea Petermann-Meyer**
“There are many women for whom their breasts are a key element of their femininity. There are other women for whom the breast is not as important. With regard to breast reconstruction, it is only the patient’s opinion that counts.”
Radiation therapy is an integral part of the treatment of breast cancer. It helps to prevent local recurrences by destroying any tumour cells that are still present in the breast or in the area of the scar. Radiotherapy can commence two or three weeks after surgery, that is, as soon as the surgical wound has had a chance to heal and plans have been concluded for the radiation treatment. In individual cases, radiation therapy is already initiated during the operation, and this is referred to as intraoperative radiation. By irradiating the tumour bed during surgery, the duration of postoperative radiation can be shortened by one or two weeks and the chances that all of the tumour cells have been destroyed on site is increased.

The exact time for beginning radiation therapy also depends on whether chemotherapy will be required. If so, then radiotherapy is only begun after the chemotherapy has been completed.

The radiation, which is administered in about 30 daily sessions, only takes a few seconds. There is a distinction between the single daily dose and the total dosage administered over the entire course of the treatment. The total dose is divided into single part-doses (known as fractions). The total dose depends upon the goal of therapy (curative versus palliative) and the localisation of the tumour. As administered today, radiation therapy controls and directs the radiation intensity in such a way as to normally prevent any serious burn injury to the skin.

Radiation therapy is also used for treating metastases in advance stages of the illness. In this situation the primary aim of treatment is to control pain and – depending on the location of the metastases – to prevent additional complications, such as bone fractures that can result from bone metastases. A particular site can only be treated once with radiation, since excessive radiation can damage the genetic material in the cells.

Side effects
One unpleasant side effect that is rather common is reddening of the skin in the irradiated area, which can become quite sensitive. During the period that radiation treatment is administered, it may be uncomfortable for the skin to be in contact with water so that it should only be powdered clean. In other respects, many breast cancer patients do not experience radiation therapy as very stressful. Frequent side effects include fatigue and malaise. As the radiation therapy continues for a longer time, these symptoms do tend to increase, but they typically disappear rapidly upon conclusion of the treatment.

Prof. Dr. med. Nadia Harbeck
“Today's modern radiotherapy has the capacity to direct the radiation very precisely to the areas that need to be irradiated. Thus, the surrounding tissues, the heart, and the lungs are spared. For this reason, you should not usually anticipate any major side effects.”
Similar to radiotherapy, the success of chemotherapy depends on the fact that the medications administered (cytostatic agents) primarily attack rapidly growing cells such as cancer cells. In breast cancer treatment, it is typical to use several cytostatic agents in combination in what are known as protocols. In the event of recurrence, the aim of chemotherapy is to stop the spread of the breast cancer and control the symptoms of the disease. A less aggressive form of combination chemotherapy (treatment with two or more medications) or monotherapy is better suited for achieving these goals in more moderate stages of breast cancer. In situations of rapid progression or an unfavourable prognosis, however, it makes sense to opt for more aggressive chemotherapy. The number of treatment cycles and the forms of administration depend on the specific chemotherapeutic agents to be used. In these circumstances, chemotherapy may be continued until there is evidence of progression of the tumour. Another strategy is to suspend chemotherapy once full remission (complete disappearance of visible tumours) or stabilisation of findings has been accomplished, and then to resume chemotherapy as soon as the tumour progresses.

Chemotherapy is administered in multiple cycles according to a strict schedule. Between cycles of administering the medications, which often take place weekly or every three weeks, there is an appropriate pause.

Different combinations of chemotherapeutic agents are employed. The choice is determined by current therapy guidelines and an assessment of the patient’s individual situation. Today, chemotherapy combinations with anthracyclines and protocols using the medication class called taxanes have become established. Frequently, chemotherapy can be administered on an outpatient basis, that is, the patient can go home right after receiving the medication. This is also true for patients suffering from advanced mammary carcinoma. For example, the patient may receive an infusion at the hospital or oncology practice in the morning and go directly to work or home right afterwards.

Besides the usual infusion therapies, there are chemotherapy treatments available in pill form for treating metastised breast cancer, and this can avoid such frequent visits to the doctor’s surgery or the hospital. The oral medication contains an active substance with a particularly intelligent mode of action. The medication is only transformed into the active substance when it reaches the tumour tissues, and as a result, it causes fewer side effects even though it is still just as effective.

Side effects
Since patients often need frequent infusions during chemotherapy, they are provided with what is known as a port system, which is placed under the skin. A port system is a metal chamber (port chamber) about 4 cm in size that is implanted under the skin below the clavicle. A thin plastic cannula leads from the chamber to the central veins close to the heart. One advantage of the port system is that the patient does not need to have a new vein entry set up for each infusion, and another advantage is that the medications can be administered more easily. The port is removed upon completion of the chemotherapy.

In the course of chemotherapy, highly active cell poisons are administered to the body through the bloodstream and these substances kill rapidly growing tumour cells. However, normal body cells that grow rapidly are also affected, such as the hair, which typically falls out completely during the therapy.

Prof. Dr. med. Nadia Harbeck
“Chemotherapy is one element in our treatment, but perhaps it is no longer the most important one.”
healthy, frequently dividing cells such as the hair follicles, the bone marrow, and the mucous membranes, it typically causes side effects that include hair loss, weakness, nausea and vomiting. The hair will grow back within three to six months after conclusion of the treatment. The other acute side effects also disappear once no further cytostatic agents are being administered. In recent years, the treatment process has continuously improved. Today there is a wide choice of medications available that are highly effective to combat side effects such as nausea and vomiting, and thus it is possible to minimise the burden of side effects from chemotherapy.

The “Oncology Guidelines Programme” of the Association of the Scientific Medical Societies in Germany (AWMF) has compiled the most up to date current guidelines for the diagnosis, treatment and aftercare of mammary carcinoma, specifically intended for patients. You can find the 2010 patient guideline, “Breast Cancer 1: initial presentation and DCIS - a guideline for patients” and the 2011 patient guideline “Breast Cancer 2: advanced disease, recurrence and metastasis” at: www.leitlinienprogramm-onkologie.de/Patientenleitlinien.8.0.html

In addition, the Arbeitsgemeinschaft Gynäkologische Onkologie e.V. [Working Group on Gynecological Oncology] (AGO) has published an up-to-date patient guide: www.ago-online.de/fileadmin/downloads/pdf/2012/AGO_Patienten_2012_Buch.pdf

Each of these brochures informs you about things you can do on your own, about the advantages and drawbacks of different tests, and about important questions that you should discuss with your doctor, also patient rights and useful addresses.

“This year, many people have said to me – so, you’ve come through it all, and now you can write it all off. And you know, I thought: No, I really don’t want to write it off. I have had so many wonderful experiences during this year.”

Ute (55)
Hormones are the body’s “messenger substances” that regulate processes such as growth, metabolism and sexual behaviour throughout the course of a person’s life. Oestrogen, which is mainly produced in the ovaries, stimulates the growth of various cells in the body via hormone receptors. Certain tumour cells also have such receptors (or binding sites) for oestrogen, and receive their stimulus for growth from these receptors. By employing anti-oestrogen drugs it is possible to inhibit or even block this hormone, and thus the growth of the tumour.

Newer substances act to block oestrogen production with the same treatment goal. They are an effective treatment for breast cancer. In early stages, when there is a particularly favourable risk profile, anti-hormone therapy may be used as the sole post surgical treatment so long as the tumour cells are receptor positive, that is, carry large numbers of hormone receptors on their surface. In other risk groups, anti-hormone therapy is used subsequent to radiotherapy or combined chemotherapy/radiotherapy, and then continued for the five-year period following primary treatment.

There are a number of different substances used for anti-hormone therapy. The choice of medication depends mainly on whether the breast cancer patient is pre-menopausal or post-menopausal.

**Anti-oestrogens**
Anti-oestrogens, medications that occupy oestrogen receptors, can be administered in tablet form. In this way, they prevent oestrogen from stimulating further growth of the tumour. However, the lack of oestrogen (similar to the use of aromatase inhibitors) has a negative impact on bone density – which can lead to osteoporosis – and thus, it may be advisable after consulting with your physician to take supplemental calcium or Vitamin D. Exercise can also have a beneficial effect in preventing osteoporosis.

**Aromatase inhibitors**
Taking aromatase inhibitors prevents oestrogen from being produced, so that tumour growth cannot be stimulated.

**Oestrogen receptor antagonists**
“Pure” oestrogen receptor antagonists occupy the hormone receptors while also accelerating the breakdown of the receptors. Thus, their mechanism of action is different from all other anti-hormone therapies and is still an option for those patients whose breast cancer is no longer responsive to anti-oestrogens or aromatase inhibitors. “Pure” oestrogen receptor antagonists are administered in the form of a monthly injection.

**GnRH analogues**
Younger women, in whom most of the oestrogen is produced in the ovaries, are also given GnRH analogues. Once every four weeks, an implant is placed under the abdominal skin, which slowly releases the active substance; this has the effect of preventing the ovaries from producing oestrogen. GnRH analogues are administered in combination with Tamoxifen or aromatase inhibitors, since they do not prevent the production of oestrogen that takes place in the muscles.

**Progestins**
In the class of progestins (gestagens), higher doses of progesterone, which is another female sex hormone, can inhibit the growth of hormone receptor positive tumours. Due to their many side effects (weight gain, fluid retention, increased risk of thrombosis and embolism), progestins are only used for treatment when other anti-hormone therapies are no longer effective.
Side effects
For most patients, anti-hormone therapy has significantly fewer side effects than chemotherapy. Therefore, it is the treatment of choice for hormone receptor positive tumours. In 60 per cent of patients, it results in remission of their symptoms. Possible side effects of anti-hormone therapy include typical menopausal symptoms such as hot flushes, sweating, sleep disturbance, mood swings and weight gain. Here, after consultation with the physician, sage tea, St. Johns wort or antidepressants may be helpful to treat these side effects. While women tend to find these symptoms much less burdensome during menopause, anti-hormonal therapy in young women can signify the end of their fertility.

Additional side effects that may affect all women include vaginal dryness and loss of libido. Lubricants and oestrogen gel may be helpful for vaginal dryness. Loss of libido should never be regarded as a personal failure, since about 20 per cent of patients ultimately complain of this side effect. If the decrease in sexual energy leads to psychological stress, supportive psychotherapy may be helpful. In addition, patients should not hesitate to discuss these problems with their doctor or a self-help group. It is very important that women consult a doctor to discuss these side effects before singlehandedly deciding to discontinue the medication, so that all possible treatment options can be considered.

Despite such possible side effects, one should not underestimate the effectiveness of anti-hormone therapy. It helps to prevent further growth or new formation of cancer. Anti-hormone therapy can also be used successfully in women whose cancer has already spread (metastasised).

Prof. Dr. med. Nadia Harbeck
“Patients should let their physician know what is closest to their hearts. If a patient can no longer bear a treatment, she should communicate this to her doctor. Naturally, there are alternatives. Frequently, it is possible to prevent the side effects. However, we can only help if we are asked, and for this reason, my appeal is that patients should talk with us.”
Antibody therapy

Antibody therapy belongs to what are known as “targeted therapies”. Compared to chemotherapy, these treatments have virtually no impact on healthy tissue. Antibody therapies block specific characteristics of the cancer cells, thus leading to a halt in the growth of the tumour. This treatment approach has already shown significant success, specifically for breast cancer.

There are specific growth factors similar to hormones that regulate the maturation of cells in the body through receptors. In the case of breast cancer, the HER2/neu protein, which is a receptor protein found on the surface of normal body cells, plays a special role.

HER2/neu receptors also may occur in larger numbers on the surface of breast cancer cells. This is true for approximately 20 per cent of women with breast cancer. In these women, the number of receptors is often increased to 100 times the norm. Such over-expression of HER2/neu means faster tumour growth and greater risk for the occurrence of metastases. Some years ago, researchers succeeded in developing an antibody against the HER2/neu protein, which blocks receptor sites. Growth signals can no longer be transmitted, thereby halting further growth. In addition, the tumour cells are marked in such a way by having their surface occupied by the antibodies that the body’s immune cells are able to attack and destroy them.

Unlike chemotherapy, this kind of treatment only targets and damages the cancer cells.

When there are excessive HER2/neu receptors on the tumour surface, HER2 antibody therapy has become part of standard treatment for both metastatic breast cancer and early stage breast cancer. It has been shown that the preventive administration of antibodies in conjunction with chemotherapy can prevent relapses and thus contribute to a cure.

In more advanced stages, antibody therapy can be used either alone or in combination with chemotherapy or anti-hormone therapy. Many studies have shown that tumour growth can be slowed even in advanced HER2/neu positive breast cancer.

In early stage breast cancer, antibody therapy is administered for one year. The treatment of metastatic breast cancer is continued for as long as the medication continues to show a positive effect and the cancer has been arrested.

If disease progression occurs despite HER2 antibody therapy, there are other specific treatment options directed against the HER2/neu receptors, including what are known as ‘small molecules’. Small molecules penetrate the cancer cells and block the tyrosine kinase, the sensitive portion of the receptors inside the cells. In this way, the growth factor signals that unleash the process of cell division are no longer transmitted and, in turn, tumour growth is halted. Treatment with small molecules is conducted in conjunction with chemotherapy.

Side effects
Flu-like symptoms may occur during the infusion, such as fever and chills. Such side effects are most likely during the initial infusion, and are much less common in subsequent infusions. Often, a brief interruption of the infusion can stop the symptoms, and then the infusion can continue. If necessary, anti-flu medication, such as paracetamol (acetaminophen), may be used to help manage the symptoms.

As a precaution, all patients receiving HER2-antibody therapy have their heart function monitored before and during the treatment. This is generally done by means of an electrocardiogram (EKG) and an ultrasound examination of the heart, which are repeated at regular intervals.

Essentially, antibody therapy is better tolerated than chemotherapy since its highly targeted effects cause less impact on healthy cells.

Many breast cancer tumour cells carry surface receptors (1). When HER2 antibodies occupy these receptors, the cancer cells receive fewer growth-promoting signals (2). This significantly slows their multiplication, ideally leading to the death of the cancer cells. Whether a patient benefits from such HER2 antibodies depends on whether her tumour cells carry the HER2 receptor protein or not. Therefore, as a rule, the first step is to determine the HER2 receptor status.
Anti-angiogenesis

There are a variety of therapeutic options available for patients diagnosed with advanced or metastatic breast cancer. For some years now, these options have included the use of what are known as angiogenesis blockers.

How does a tumour grow?
Angiogenesis is a term that refers to the growth of new blood vessels, so an angiogenesis-blockade refers to blocking the formation of new blood vessels. When a tumour first starts to grow, it can nourish itself with nutrients and oxygen drawn from its immediate surroundings. But once it reaches a size of about two millimetres, the tumour has to create its own blood supply, and for this purpose, it releases messenger substances that stimulate penetration of new blood vessels into the tumour. The most important class of such vascular growth factors are known as VEGF (vascular endothelial growth factors). As soon as vascular cells receive the signal from these growth factors, they form new blood vessels, and from that moment on, the new vessels supply the tumour with nutrients and oxygen. This allows the tumour to grow and to spread (metastasise).

Inhibiting tumour growth
An antibody manufactured through biotechnology inhibits new vessel formation by specifically intercepting the VEGF growth factors, thus preventing them from having their effect. It is important to employ the angiogenesis blocker very soon after it has been determined that the tumour is progressing in order to block new vessel formation as soon as possible and thus halt tumour growth.

The aim of this treatment is to improve the tumour’s responsiveness to chemotherapy and delay further progression of the disease for as long as possible. Therefore, angiogenesis blockers are administered first in combination with chemotherapy and subsequently continued for as long as they demonstrate effectiveness. The infusion generally takes places once every three weeks.

Side effects
Angiogenesis blockers can cause nosebleeds and raised blood pressure in some patients. Therefore, the blood pressure should be monitored regularly. It is important that the physician be informed as rapidly as possible about any side effects such as dizziness, nosebleeds, etc. that may indicate raised blood pressure or a bleeding tendency in order to rapidly initiate appropriate treatment.

Tumour cells release VEGF vascular growth factors, which send signals to the blood vessels and thereby regulate their growth (1). Using these new vessels, the tumour can supply itself with nutrients and oxygen (2). The antibody binds and blocks the vascular growth factors (VEGF) (3). Blood vessels in the tumour regress and new blood vessel formation is blocked. The tumour is no longer adequately nourished and “starves”.
The skeletal system is the site where breast cancer cells most often form metastases. About two thirds of women with advanced mammary carcinoma will develop bone metastases at some point in the course of their illness. It is primarily the axial skeleton that is involved, that is, the spine, the pelvis, the thigh bones (femurs) and the ribs.

There are cells that build bone and other cells that break down bone. Normally, bone construction and bone destruction are kept in balance. However, many tumour cells have the property of activating the cells that break down bone substance, known as “osteoclasts” or bone-eating cells. The rapid increase in bone breakdown can lead to calcium being leached from the bones into the blood. The ensuing elevation of the blood calcium level can affect a number of metabolic processes, and this, in turn, can result in major complications. Increased bone destruction also reduces the calcium content in bones, thereby reducing bone strength. The consequences may include bone fractures, collapsed vertebrae and bone pain.

Bone metastases often remain undetected for a long time. The first indication of the presence of bone metastases is usually pain in the affected area of bone. At the time bone metastases are discovered, over half of affected patients report that they have had pain for a long time. For this reason it is important to take seriously any newly arising and persistent pain in a particular section of the skeletal system and to consult a physician.

Today, bisphosphonates are used to treat bone metastases. These medications block further bone destruction, and thus also help both to regulate the blood calcium level and to provide effective relief for bone pain, something that is of enormous importance for the quality of life. When used for bone metastases, bisphosphonates are administered on a life-long basis.

**Use and side effects**

Bisphosphonates are either administered as tablets to be taken daily or as a monthly infusion. They can be combined with other treatments, and as a rule, they are well tolerated. Intravenous infusion of bisphosphonates can initially result in flu-like symptoms, and when taken orally, the tablets can cause nausea and gastrointestinal symptoms. Since bisphosphonates affect bone metabolism, patients should let their dentists know they are taking bisphosphonates prior to surgical procedures on the jaw and discuss whether it is necessary to interrupt the bisphosphonate therapy.

There is progress being made and new discoveries emerging in the field of bone metastases. In the interim, antibodies have become available that can be used to treat bone metastases. These antibodies are administered subcutaneously (injected under the skin).

**Jutta (68)**

“When the doctor doesn’t insist on a treatment and you know you decided on it yourself, you also feel quite different about it, and it’s easier for you to stick to the treatment.”
Breast reconstruction

The sole critical element in the question of whether and when to consider breast reconstruction after surgery is the wish of the woman who is affected. Possibilities include immediate reconstruction after tumour removal and later reconstruction, which of course involves an additional surgical procedure. Many women consciously choose not to have breast reconstruction and to have a mastectomy. They feel a greater sense of safety from more radical surgery or prefer to avoid the radiation treatment that accompanies a breast-sparing operation.

For making this decision, it is important that the patient first be thoroughly informed by her treating physician or surgeon. The doctor should provide exhaustive information about the advantages and drawbacks of different techniques. An additional help for decision-making is provided by discussions in self-help groups. Here, the members of the group have each had unique experiences and can thus speak first-hand about their personal impressions.

Basically, the goal of breast reconstruction is to replace the tissues that have been removed in such a way that the external appearance of the operated breast resembles that of the healthy breast.

“I thought: Of course I’m still me. My spirit has certainly been dented, but I’m still myself. My hair will grow back. And at the same time, the thought came to me: I’m going to have my breast reconstructed. I know it can be done and that I’ll be a complete woman again on the outside as well.”

Peggy (40)
Reconstruction after breast-sparing surgery

Today about 80 per cent of women can be treated with breast-sparing (or breast-conserving) surgery. For very small tumours, no additional surgical measures are required, since the appearance of the breast is only minimally affected by procedures of this kind. The situation is different for larger tumours where a relatively more significant amount of breast tissue must be removed during the operation. This may result in a significant size difference between the two breasts, which may be very distressing for the woman’s aesthetic sensibility. These effects need to be taken into consideration when planning the surgery.

To prevent size differences, one can adapt the size of the non-involved breast at the same time or at a later point (breast reduction plastic surgery). Depending on the location of the tumour, the nipple may need to be removed in order to achieve the desired margin of safety. For optimal cosmetic treatment results, it is advisable to reconstruct the nipple. Today, it is possible to recreate a nipple using material from one’s own body or by tattooing.

Reconstruction after mastectomy

The following procedures are used for breast reconstruction:

- The skin expander technique using foreign synthetic materials
- Reconstruction with skin-muscle flaps (without use of foreign materials)
- Reconstruction using one’s own tissue plus a silicone gel or saline solution implant.

**Skin expander technique**
The aim of this method is to first stretch the skin in the operative area and subsequently reconstruct the breast using an implant. For this purpose, plastic cushions are placed under the breast muscle and filled with salt solution in order to achieve the desired level of stretching of the skin for the subsequent treatment. This can be accomplished in about eight weeks. In a second operation – usually performed a couple of months later – the final prosthesis is placed under the skin.

However, this surgical technique may cause the tissues to harden and become fibrotic (that is, the amount of connective tissue increases). The skin’s healing process is also made more difficult by the stretching process, and this can cause delayed wound healing. Thus the method is sometimes associated with a poorer cosmetic outcome – especially when considering long-term results.

**Reconstruction with skin-muscle flaps (tissues from one’s own body)**
In this method, the surgeon does not use any foreign materials, but instead uses skin-muscle flaps from the back (latissimus dorsi flaps) or the abdominal wall (transversus rectus abdominis flaps, or TRAM flaps for short) to model a reconstructed breast.

Dr. med. Andrea Petermann-Meyer
“A woman’s relationship to her own breast changes over time. At the beginning, her concern is for a maximum of safety with regard to the cancer. Many women are at first quite prepared to sacrifice their breast for this purpose. But later on, it often becomes clear that it might be nicer to have a breast made of one’s own flesh and blood.”

Necrosis (death) of the skin – caused by disruption to the blood supply after harvesting from the back or the abdomen – can be effectively prevented using free or pedicled microvascular grafts.

In the pedicled variation, the skin-muscle flap is transferred from the back or the abdomen to the amputated breast without cutting the blood vessels. This results in a temporary bridge, similar to a pedicle, which continues to supply the transplanted body part with blood and nutrients for the time it take to grow into the breast area and become integrated into the circulatory system through newly formed blood vessels.

In the free microvascular variation, the surgeon cuts the skin-muscle flap free from its vessels and uses it to reconstruct the breast.

Using a microscope, the surgeon connects the ends of the vessels in the transplant to the axillary vessels.

Surgeons typically reconstruct a small breast using a latissimus dorsi flap from the back. The TRAM flap is better suited for reconstructing larger breasts. It generally takes eight weeks for the skin flaps to grow in.

Breast reconstruction using tissue from one’s own body plus an implant
This procedure is also performed using the methods described above. If it is impossible to achieve the desired volume of the surgically treated breast using only added muscle, then a supplementary implant made of silicone gel or saline solution can be inserted.

Side effects
A sense of numbness and some degree of sensitivity to touch can often persist in the operated area, since important nerves have sometimes been cut. After total mastectomy, there may also be long-term restriction of arm movement, since extensive scar formation may lead to a feeling of tightness. If the breast is not reconstructed and the patient is not wearing a prosthesis, postural problems may develop due to the imbalance in weight. Targeted physiotherapy can help to relieve or entirely resolve these symptoms.

Prof. Dr. med. Ulrike Nitz
“These days, 70 to 80 per cent of patients have breast-sparing surgery. A woman only has to lose her breast if she has inflammatory breast cancer.”
Rehabilitation

Cancer rehabilitation has become an integral part of standard treatment for breast cancer, and all patients in Germany have access to rehabilitation. As a rule, the following therapies and services are provided in the course of a three to four week stay at a rehabilitation centre:

- Exercise and movement therapies
- Nutritional counselling and education
- Treatment of lymphoedema
- Psychological counselling and therapies
- Relaxation, art and occupational therapies
- Counselling about social and social security issues
- Assistance in applying for services
- Measures to support occupational and social integration
- Planning medical follow-up care

These programmes are intended to help the patient return to her previous level of function – even after a recurrence – and thereby accelerate the process of reintegration. The patient can also apply for such services at a later point if she has returned home but is finding she has problems coping with daily life.

Besides activities designed to help physical, spiritual and psychological healing, rehabilitation offers the breast cancer patient a chance to process the stresses of her cancer diagnosis and treatment in a quiet place. At home with her family, she often faces a double burden, and this stay at the rehab centre can help her to practice planned changes in behaviour in advance, with a view to later implementing them in her daily life back at home.

Clearly rehab programmes are not an obligation. Each patient can decide for or against them as she wishes. However, it is important to discuss the benefits and drawbacks with her physician. Sometimes a rehab programme can take place at a day clinic.

If a patient decides in favour of a rehabilitation programme, she needs to submit a personal application. During her hospital stay, clinical social workers can provide assistance in filling out an application and regional REHA service centres can assist her on an out-patient basis.

The choice of rehabilitation clinics is usually limited according to health insurance membership. In many federal states, there are institutions that assume responsibility for assigning patients to a rehab centre. However, it is always advisable for patients to participate in the selection of a rehabilitation programme, since it is also important to consider the centre’s location. Many institutions are located in the low mountain ranges, and only a few near the sea. For patients with other limitations in their mobility, perhaps as a result of joint or heart problems, it is advisable to find a rehabilitation clinic in a level location.

Many patients are concerned about accepting this further treatment. They don’t want to put an additional burden on their families or are worried that more contact with other cancer patients will adversely affect their mood. Yet, before making a decision for or against rehab it is advisable to first inform oneself thoroughly about a potentially suitable institution and to discuss the programme with one’s physician.

Ute (55)
“I was more or less talked into going to rehab. I went there quite sceptically. Yet, within a day we had become a terrific group of women, and we still keep in contact today. It was a wonderful time that did me a lot of good, a time I could just concentrate on myself. I found my creative streak there.”
Additive treatment methods

Many women ask themselves: “What else can I do to become healthy again? Are there alternative or supplementary treatment methods besides those of conventional medicine? You hear and read a great deal about supposedly effective ‘alternative’ cancer treatments – how much of this can I or should I believe? Which methods might make sense for me?”

Every patient should feel free to ask a trusted physician to advise her about existing “additive therapies” and to what extent they would be compatible with the standard “conventional medical treatments” she is currently receiving. Discussion with the doctor is important in order to evaluate whether undesirable interactions might occur with her current treatment and whether the additive therapy might interfere with the effectiveness of her medical treatment.

Mistletoe, enzymes, trace elements and vitamins can all help combat such side effects of treatment as nausea and weariness, and thus contribute to improving one’s overall feeling of well-being. However, none of these treatments can replace conventional medical treatment and their use should be discussed with the doctor in every instance.

It is important for all cancer patients to be extremely wary about naturopathic products and promises. There are an endless series of “miracle cures” on the market, especially on the Internet. They play upon the insecurity that comes along with a cancer diagnosis and take advantage of it. It makes sense to be suspicious if a product is advertised to cure all forms of cancer without any side effects. A place to find reliable advice is the “Institute for scientific evaluation of naturopathic methods” at the University of Cologne.

Mistletoe preparations

Although various mistletoe preparations have been used in cancer therapy for years and their effectiveness has been shown in different studies, their use to supplement standard conventional medical treatment has not been clearly established. For some patients with particular immune defects, the active substances found in mistletoe known as lectins (compounds of protein and sugar) can be used specifically to augment the immune system. In addition, mistletoe preparations are said to have a moderating impact on the short and long-term side effects of chemotherapy and radiation therapy.

After appropriate instruction, mistletoe preparations can be injected under the skin (subcutaneously) by the doctor or by the patient herself. However, allergic reactions may occur in many cases, such as intense redness at the injection site, fever, headache or circulatory problems.

Prof. Dr. med. Nadia Harbeck

“It is understandable that patients want to personally contribute to improving their chance of a cure. This is a good occasion to clearly state: there is no cancer-specific diet. You should not avoid certain foods in order to fight the tumour. What is important is to have a balanced and healthy diet during your treatment and afterwards.”
Chronic fatigue secondary to cancer, also referred to as the exhaustion syndrome, may affect many cancer patients during treatment, and in a few patients may persist for quite a while even after they have completed successful treatment. In the advanced stages of breast cancer, more than half of patients are affected. Fatigue can appear without any preceding unusual exertion and without the possibility of full recovery after resting. As a result, it can have a major adverse impact on the patient’s quality of life and significantly affect the course of the treatment.

Sometimes it is the tumour itself that is responsible for the fatigue. This may be explained by different tumour-related changes that continuously exhaust the body’s energy reserves. The cancer treatment may also cause fatigue. Treatment takes a lot out of patients and can lead to major physical as well as emotional exhaustion. This is because chemotherapy and radiation therapy not only affect cancer cells but also place stresses on the body as a whole. The body’s immune defences may be reduced by the suppression of blood formation, (due to leukopenia, a reduction in the number of white blood cells). There may be increased risk of bleeding (thrombocytopenia) and chronic anaemia may occur (a lack of red blood cells, or erythrocytes).

**Anaemia**

The function of the erythrocytes in the blood is oxygen transportation. Oxygen is transferred to the erythrocytes in the lungs from inhaled air and then supplied to the whole body through the circulatory system. The fewer red blood cells are present, the poorer the oxygen supply to the body’s organs. The production of red blood cells in the bone marrow is stimulated by the hormone erythropoietin.

Both the tumour and chemotherapy can cause a deficiency in erythropoietin and significantly impair blood formation. The consequence is different degrees of anaemia, which can go on to weaken the entire organism due to chronic oxygen lack.

**Acute and chronic course**

In general we can distinguish two forms of fatigue: acute fatigue, which is seen in virtually all patients and may be an expression of the cancer or caused by anaemia, and chronic fatigue, which represents exhaustion lasting for more than a year, which can significantly affect the patient’s daily life.

Relatively little is known at this time about the causes of the tumour exhaustion syndrome. There is need for further clarification, especially regarding the more chronic forms that can last for more than a year. There are questionnaires currently available that allow the occurrence and the course of tumour-related fatigue to be accurately tracked.

**Possible treatment options**

The treatment of fatigue occurring in the acute phase of cancer treatment is to treat the anaemia and to correct any tumour or treatment-related metabolic disturbances. If anaemia is present, it is possible to significantly improve the patient’s general sense of wellbeing by raising the haemoglobin level. Given this possibility you should consult your doctor at the first signs of weakness. Specific treatments that have proven effective for chronic fatigue include physical training and psycho-oncological interventions. Should these measures prove insufficiently helpful, you can consult a fatigue specialist.

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Dr. med. Andrea Petermann-Meyer:

“Physical activity, sports and relaxation exercises play a major role in overcoming an illness. One can further motivate patients to take these steps with the information that exercise also aids survival. Many studies have unequivocally shown that exercise reduces the rate of new illness and metastases.”
Pain and its treatment

Pain can become an enormous burden for patients with advanced breast cancer and significantly impairs their quality of life. Should the underlying cause of the pain – the tumour or its metastases – not be directly treatable, effective pain management becomes one of the most crucial elements in the patient’s medical care. Pain treatment needs to be individually adapted for each patient. More than ever before, it is possible today to successfully relieve tumour pain.

Treatment may be administered using tablets, drops, an infusion or patches. Opioid morphine derivatives are the most effective pain medications available. Today, prescribing them is much less complicated than it once was, and the patient’s fears of dependency are unfounded.

For effective and sustained pain relief it is critical that the patient take the medications according to a fixed regimen and not wait until the pain becomes acute. Regular, preventive administration helps to keep pain from occurring in the first place. Pain always has a psychological aspect; for example, it unleashes anxiety, which in turn can result in increased pain sensitivity. For this reason, taking antidepressants may help support effective pain management.

Specially trained pain therapists are clinicians with extensive experience in treating pain. These therapists, along with “pain clinics” can be important contact points for managing acute and severe pain.

“Medicine has come a long way, so that everything is done to make you feel well. I have to say, in part I just felt good because people were paying attention to me at last.”

Heike (53)
The post-treatment period

As a rule, follow-up examinations for either initial or recurrent illness take place several times a year during the first five years after diagnosis, but after the sixth year, the frequency decreases to only once a year. If breast-sparing surgery was performed, the other breast must be examined as well, and after mastectomy, the area of the removed breast must also be examined.

While treatment is very stressful for women, it also provides a sense of security. The plan of action is clear – women are in constant touch with medical personnel, and thus have their questions and uncertainties addressed right away. After treatment concludes, a difficult period begins for many women – something for which they are often unprepared.

The people around the patient assume that with the successful conclusion of treatment, everything is going well and the woman has resumed her “normal” life. However, along with this expectation come increased demands on the recovered patient. She is expected to resume all the various roles she played before her illness: the roles of mother, employee or partner. While many women meet these demands with relative ease and experience an ideal reintegration into society, others feel overwhelmed and under a great deal of pressure. They may often respond by feeling powerless, resigned and sad that they cannot meet everyone’s expectations. These feelings not infrequently intensify the fear of recurrence and doubts about their own femininity, all of which can be a tremendous burden.

In this phase patients are well advised to actively seek out help and discover for themselves which kind of support would be best. Contact with patients in similar circumstances has been specifically shown to be very helpful. Discussions in a self-help group help each woman understand her situation better and provide her with time to find her way back to life.

In a few cases, the difficulties adapting may become so overwhelming that professional consultation and therapy may be indicated. Physicians and psychologists who specialise in this field, known as psycho-oncologists, are important contacts in this situation.

Patients who are facing a potentially incurable recurrence see themselves increasingly confronted with their own mortality. Psycho-oncologists, self-help groups and organisations can connect with these women right after the diagnosis to let them know about options for managing the illness and to provide them with guidance about life with cancer. Social counselling services are available to assist with questions in the economic and social areas. You will find information about these services in the supplement to this brochure.

Jutta (48)

“Many people say: I’m not going to a self-help group, because all they will talk about is the illness. That’s not true. We have a whole lot of fun and talk about so many subjects. It depends a bit on each of us individually. You should always try to make the best of it, and see the illness as an opportunity.”
Daily life with breast cancer: family and partnership

The diagnosis of breast cancer strikes at the heart of those affected, their families and their partners. To cope with this situation without excessively burdening individual family members, everyone must clearly understand the new life schedule for the wife and mother that results from the cancer. Each family member should have a chance to communicate his/her own experiences in open discussions. Should this prove impossible without outside support, it makes sense to include a specialised clinician who is an expert in dealing with the psychological and social aspects of cancer. The psycho-oncologist can help both the patient and her loved ones. Psycho-oncologists provide support for cancer patients in the hospital and as outpatients in their own practices.

When seeking professionals specialising in psycho-oncology, patients and their families can turn to dapo, the German Association for Psychosocial Oncology e.V.:

dapo – administrative office
Ludwigstraße 65, 67059 Ludwigshafen
Telephone: 0700-2000-6666
Fax: 0621-5929-9222
www.dapo-ev.de

In addition, hospital social service departments and self-help organisations can also provide assistance. You will find more detailed information in the supplement.

Children have an intuitive sense of when something is the matter with their mother. Depending on their age, their reactions can range from an overwhelming fear of loss to that of taking over the role of the mother in the family. Especially for children, the threat of excessive demands feels very real. In this situation the highest imperative is to speak openly with the children. The truth is the best thing for them and will help them to do much better in processing their mother’s illness. They also need the opportunity to ask questions. It is through their questions that one can sense most vividly the dangers the child feels threatened by.

The Flüsterpost e.V. is an organisation set up to serve children with a parent suffering from cancer. The association informs, advises and assists children of any age, their families and their caregivers.

Flüsterpost e.V.
Support for children who have a parent with cancer
Kaiserstraße 56, 55116 Mainz
Administrator: Karin Willmann
Telephone 06131-5548-798
www.kinder-krebskranker-eltern.de

Hildegard (65)
“Family cohesion makes an enormous difference. When there’s someone by your side at the doctor’s office or the hospital, it makes things easier.”
Daily life with breast cancer: effects on work and leisure time

For many women, along with their family life, their work is another important part of life that can be threatened by breast cancer. Even though this problem may take a back seat at the very beginning, it can take on increasing importance over time. Once the danger of death has been surmounted at the conclusion of her treatment, the patient has to determine for herself the place that work will occupy in her overall life. If she resumes her occupation, she should accept reintegration assistance in any form that is offered.

Answers to civil law and social law issues related to reintegration are available nationwide at the 21 counselling sites provided by the Independent Patient Counselling Germany (UPD) association.

Unabhängige Patientenberatung
[Independent Patient Counselling]
National Office
Littenstraße 10, 10179 Berlin
Telephone 030. 20089233
www.unabhaengige-patientenberatung.de

After completion of treatment, the patient’s status regarding occupational disability may need to be adjusted. The treating physician and the responsible authorities must come to an understanding about the extent to which requirements are met for a retirement pension. In such cases, you should consult:

Deutsche Rentenversicherung Bund
[German Pension Insurance Alliance]
Information about pensions, pension rights and rehabilitation
10704 Berlin
Telephone 030. 8651
www.deutsche-rentenversicherung-bund.de

An additional physical effect of breast cancer is lymphoedema – an accumulation of lymphatic fluid in the arm. This frequently results in restriction of mobility; something that occurs in many women who have had the lymph glands in their axilla removed surgically, and its impact can be quite variable. Many patients have to undergo continuous lymph drainage through a specific form of massage designed to return the fluid to the circulatory system.

Even if mobility is limited, the patient should still try to take part in all activities. By carefully increasing the level of activity and in consultation with the treating physician, she can discover to what limits she can push herself. This is true for all breast cancer patients, both during and after therapy. Exercise and sports are very important for the majority of affected women. Through individually adapted exercise training it is possible to prevent states of exhaustion and to improve psychological well-being. More detailed information about specialised sports groups is available from cancer counselling sites, the major self-help organisations, or your health insurance company.

Dr. med. Andrea Petermann-Meyer
“Many women experience returning to work as a real hurdle. When the woman returns to work after a year away, she will be meeting many people there who have not been involved with her so intensively during the last few months. That means she will be confronted with many questions: How are you doing? What was it like? Tell me all about it! Often, it is not so clear for the woman herself: Whom do I want to tell and how much? To what extent do I want to share this with my work colleagues?”
The question keeps coming up of how one’s personal attitude might affect the course of breast cancer. There is no definitive answer to this question as yet, since there are quite contradictory data about this subject. Thus, some indications suggest that patients who approach their cancer aggressively have a somewhat more favourable course.

The advice that all you need to do is to think positively and this will improve the course of the disease is certainly mistaken. Just as there is no such thing as a “cancer personality”, it is also true that the patient bears no guilt for her illness or its outcome. Of course, she shares responsibility for shaping the optimal course of treatment and for actively seeking the best therapy conditions. This includes making sure she is thoroughly well informed so she can adapt her own behaviour to the planned steps of treatment. It is important for every patient to get to the bottom of any fears that may come up; if she discovers the sources of her fears and gives expression to them, for example through writing, it makes it easier to overcome her fears. When patients bear in mind the challenging situations in life they have already mastered, they find it possible to discover new strength. Relaxation, bicycle riding, swimming, or interacting with the good things in life can all help develop better ways of coping with the illness.

When asked what they would recommend to other women as ways to cope better with their illness, breast cancer patients offered the following suggestions to the Women’s Self Help after Cancer e.V. Organisation:

- Set (achievable) goals for yourself;
- Make plans;
- Let yourself ask or redefine questions about the meaning of life;
- Take joy in beautiful things;
- Set (doable) tasks for yourself;
- Actively contribute to combating the cancer (for example, by means of nutrition, exercise, and a positive attitude to life);
- Exchange experiences with other women;
- Keep participating in life and maintain your curiosity;
- Throw off “excess baggage”;
- Keep being the person you are.

“Dancing has given me incredible strength. When I’m dancing I can turn everything off. As soon as I’m dancing, I laugh and I am happy.”

Heike (53)
About the campaign

Since 2001, the Germany-wide campaign, “Through my breast to my heart – the challenge of breast cancer” has been providing valuable information to affected women and their families. It is sponsored by the Roche Pharma AG and advised by the Deutsche Krebgesellschaft [German Cancer Society] and die German Society for Senology.

As they seek answers from doctors, books or the Internet, patients are confronted with a huge amount of information, and this often evokes further questions and leaves them feeling uneasy. In response to this need, the campaign “Through my breast to my heart – the challenge of breast cancer” hopes to communicate basic knowledge about breast cancer along with specific information for patients about treatment options and management strategies.

The comprehensive collection of coordinated and progressive information materials, including brochures and films well as the lecture series “German cities against breast cancer”, offers comprehensive and structured assistance for managing this illness. Projects such as the documentation volume “Thoughts about breast cancer”, the illustrated book, “Images of Life”, and the brochure, “How do I tell those dearest to me?” provide additional emotional support. In addition, the Breast Cancer Journal and the Screening Passbook provide meaningful help for women.

Further information materials

The campaign “Through my breast to my heart – the challenge of breast cancer” is comprised of the following media, which will be distributed free of charge to those who are interested:

The challenge of breast cancer – an informational film for women with early or advanced breast cancer
Diagnosis, treatment, effects of the illness on relationships, family and work, 62 minutes and 21 minutes, available as a DVD; in English, Russian and Turkish at www.brustkrebszentrale.de

Savouring life – cancer, crisis, strength
A film about the processes of change that can be set off by being ill with cancer; 70 min, available as a DVD

Breast Cancer Journal
for clear and complete documentation of the illness

Screening Passbook
for routine screening examinations at the gynaecologist

In addition to these materials, clinical social services and self-help organisations also provide assistance. You will find more detailed information about them in the supplement.

All the materials are available from the following address:
Durch die Brust ins Herz [Through my Breast to my Heart]
Postfach 511170 50947 Köln

or from www.brustkrebszentrale.de.
Useful addresses

**BRCA-Netzwerk – Hilfe bei familiärem Brustkrebs und Eierstockkrebs [BRCA Network – Help for familial breast cancer and ovarian cancer]**
Freie Bitze 1, 53639 Königswinter
www.brcanetzwerk.de

**Brustkrebs Deutschland e.V. [Breast Cancer Germany Association]**
Charles-de-Gaulle-Straße 6, 81737 Munich
Telephone 0800. 0117112
www.brustkrebsdeutschland.de

**Deutsche Fatigue Gesellschaft (DFaG) [German Fatigue Society]**
Maria-Hilf-Straße 15, 50667 Köln
Telephone 0221. 9311596
www.deutschefatiguegesellschaft.de

**Deutsche Gesellschaft für Senologie [German Society for Senology]**
Hausvogteiplatz 12, 10117 Berlin
Telephone 030. 514883345
www.senologie.org

**Deutsche Krebsgesellschaft e.V. [German Cancer Society]**
Kuno-Fischer-Straße 8, 14057 Berlin
Telephone 030. 3229329-0
www.krebsgesellschaft.de

**Deutsche Krebshilfe e.V. [German Cancer Aid]**
Buschstraße 32, 53113 Bonn
Telephone 0228. 72990-0
www.krebshilfe.de

**Frauenselbsthilfe nach Krebs e.V. [Women's Self Help after Cancer]**
Thomas-Mann-Straße 40, 53111 Bonn
Telephone 0228. 33889-400
www.frauenselbsthilfe.de

**INKA – Informationsnetz für Krebspatienten und Angehörige e.V. [Information Network for Cancer Patients and their Families]**
Reuchlinstraße 10-11, 10553 Berlin
Telephone 030. 44024079
www.inkanet.de

**Institut zur wissenschaftlichen Evaluation naturheilkundlicher Verfahren**
Joseph-Stelzmann-Straße 9, Building 35a, 50931 Cologne
Telephone 0221. 478-6414
www.iwenv.de/

**Internet-Krebs-Kompass der Volker Karl Oehrich-Gesellschaft e.V. [Internet Cancer Compass]**
Branch office, Eisenacher Straße 8, 64560 Riedstadt
www.krebskompass.de

**KID – Krebsinformationsdienst**
Deutsches Krebsforschungszentrum Heidelberg [Cancer Information Service of the German Cancer Research Centre Heidelberg]
Im Neuenheimer Feld 460, 69120 Heidelberg
Telephone 0800. 4203040
www.krebsinformationsdienst.de

**mamazone – Frauen und Forschung gegen Brustkrebs e. V. [Women and Research against Breast Cancer]**
Postfach 310220, 86063 Augsburg
Telephone 0821. 5213-144
www.mamazone.de

**Mamma Mia! – Das Brustkrebsmagazin [The Breast Cancer Magazine]**
Alt Königstraße 31, 61476 Kronberg
www.mammamia-online.de

**Österreichische Krebshilfe [Austrian Cancer Aid umbrella organisation]**
Wolfengasse 4, A-1010 Vienna
Telephone 0043. 179664-50
www.krebshilfe.net

**Krebsliga Schweiz [Swiss Cancer League]**
Postfach 8219, CH-3001 Bern
Telephone 0041. 3138991-00
www.swisscancer.ch

**Bundesministerium für Gesundheit und Soziale Sicherung [German Federal Ministry for Health and Social Security]**
Telephone 0800. 151515-0
www.bmg.bund.de

**RKI – Robert Koch Institut [The Robert Koch Institute]**
Umbrella documentation of cancer and cancer register
www.rki.de

**Nationales Krebsforschungsinstitut der USA [National Cancer Institute]**
www.cancer.gov

**ICIS – Internationale Arbeitsgruppe der Krebsinformationsdienste [International Working Group of Cancer Information Services]**
www.icis.org

**Brustkrebs beim Mann [Breast Cancer in Men]**
Bonn University
www.meb.uni-bonn.de/cancernet/104410.html

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**Cancer information in other countries**

**Österreichische Krebshilfe [Austrian Cancer Aid umbrella organisation]**
Wolfengasse 4, A-1010 Vienna
Telephone 0043. 179664-50
www.krebshilfe.net

**Krebsliga Schweiz [Swiss Cancer League]**
Postfach 8219, CH-3001 Bern
Telephone 0041. 3138991-00
www.swisscancer.ch

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Umbrella documentation of cancer and cancer register
www.rki.de

**Frauenselbsthilfe nach Krebs e.V. [Women's Self Help after Cancer]**
Thomas-Mann-Straße 40, 53111 Bonn
Telephone 0228. 33889-400
www.frauenselbsthilfe.de

**INKA – Informationsnetz für Krebspatienten und Angehörige e.V. [Information Network for Cancer Patients and their Families]**
Reuchlinstraße 10-11, 10553 Berlin
Telephone 030. 44024079
www.inkanet.de

**Institut zur wissenschaftlichen Evaluation naturheilkundlicher Verfahren**
Joseph-Stelzmann-Straße 9, Building 35a, 50931 Cologne
Telephone 0221. 478-6414
www.iwenv.de/

**Internet-Krebs-Kompass der Volker Karl Oehrich-Gesellschaft e.V. [Internet Cancer Compass]**
Branch office, Eisenacher Straße 8, 64560 Riedstadt
www.krebskompass.de

**KID – Krebsinformationsdienst**
Deutsches Krebsforschungszentrum Heidelberg [Cancer Information Service of the German Cancer Research Centre Heidelberg]
Im Neuenheimer Feld 460, 69120 Heidelberg
Telephone 0800. 4203040
www.krebsinformationsdienst.de

**mamazone – Frauen und Forschung gegen Brustkrebs e. V. [Women and Research against Breast Cancer]**
Postfach 310220, 86063 Augsburg
Telephone 0821. 5213-144
www.mamazone.de

**Mamma Mia! – Das Brustkrebsmagazin [The Breast Cancer Magazine]**
Alt Königstraße 31, 61476 Kronberg
www.mammamia-online.de

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**Special Issues**

**Bundesministerium für Gesundheit und Soziale Sicherung [German Federal Ministry for Health and Social Security]**
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www.bmg.bund.de

**RKI – Robert Koch Institut [The Robert Koch Institute]**
Umbrella documentation of cancer and cancer register
www.rki.de

**Deutsche Rentenversicherung Bund [German Pension Insurance Association]**
Information about pensions, pension rights and rehabilitation
10704 Berlin, Telephone 030. 865-1
www.deutsche-rentenversicherungbund.de

**Brustkrebs beim Mann [Breast Cancer in Men]**
Bonn University
www.meb.uni-bonn.de/cancernet/104410.html
The experts in the film  (Version 2012)

Prof. Dr. med. Nadia Harbeck
Director of the Breast Centre, Hospital of the Ludwig-Maximilians University Medical Centre in Munich

Prof. Dr. med. Ulrike Nitz
Director of the Niederrhein Breast Centre, Evangelical Hospital Bethesda gGmbH Mönchengladbach

Dr. med. Andrea Petermann-Meyer
Psycho-oncologist, Aachen
The Challenge of Breast Cancer

In Germany about 72,000 women develop breast cancer every year – a diagnosis that presents an enormous challenge for those who are affected.

Even though many women can be cured today, the illness has not lost its horror. For this reason, education regarding breast cancer and its treatment represent the first important step for dealing with the illness. This is also true if the breast cancer recurs and has an effect on a woman’s life in the form of a chronic illness.

The focus of The Challenge of Breast Cancer is the courage and determination of six women with breast cancer who actively respond to the illness. Four of them report on their initial illness, and two see themselves confronted with a situation that involves metastases.

The Challenge of Breast Cancer presents a compelling picture of how these women and their partners have dealt with the illness. In clear words they portray their diverse experiences about the issues of diagnosis, treatment and aftercare, including the effects of the illness on their partner relations, their family and their work.

Recognized experts in breast cancer discuss the experiential reports from the patients and amplify them with important principles that reflect the current state of knowledge about the subject of breast cancer. A psycho-oncologist speaks about ways of enabling a better response to this difficult life situation.

The Challenge of Breast Cancer demonstrates that even in the context of facing one’s own mortality, there are a wealth of life perspectives, and in this way gives patients courage.

This DVD offers an update of the successful films The Challenge of Breast Cancer and When Breast Cancer Recurs, created by the campaign Through my Breast to my Heart.

The DVD contains two films:

1. Film The Challenge of Breast Cancer (62 min)
2. Film When Breast Cancer Recurs (21 min)