

25 Years of Cancer Information Service at the German Cancer Research Center

What women ask: Breast cancer is first on the list of topics; most questions concern treatment methods

Ever since the Cancer Information Service (KID) was established in 1986, breast cancer has been its most frequent topic. It is the subject of one fifth of all inquiries today. This is not surprising considering that the majority of KID users (65 percent) are women. And, since approximately 58,000 women are newly diagnosed with breast cancer each year, it is the most frequent cancer affecting women in Germany. "In the past year, we individually answered far more than 7,000 inquiries about breast cancer by telephone or e-mail," said Dr. Brigitte Kukla, a member of the Cancer Information Service staff.

However, there have been major developments concerning breast cancer in particular. Treatment of breast cancer has become more diverse and more individualized. Twenty-five years ago it was usually treated by radical surgery and complete removal of the breast. In addition, lymph nodes in the armpit were extensively removed. "Back then, major concerns naturally were fears of breast amputation and how to avoid or treat lymph edemas," Brigitte Kulka remembers.

Today, affected women are confronted with a great complexity of available treatment options for breast cancer such as neoadjuvant chemotherapy, i.e., treatment with cytotoxic substances before surgery; targeted drugs such as Herceptin; and various types of antihormonal therapy. Does it have to be a certified breast center or does a conveniently located local hospital offer comparable treatment quality? Is it better to opt for breast reconstruction straight away or can this equally well be done later in a second surgical procedure? Breast cancer patients have to deal with hundreds of questions – and they are much better informed now than they used to be in the early days of the Cancer Information Service. . "We hardly ever have to explain today that breast cancer may recur even after five years," says Brigitte Kukla. "Women now have very precise questions such as about particular treatments they have read about on the Internet."

New medical developments and results obtained in cancer research are regularly reflected in the questions asked at the Cancer Information Service. When the BRCA1 and BRCA2 breast cancer genes were discovered in the mid-1990s, many women who had a breast cancer case in the family turned to KID to ask whether they were themselves in danger of getting the disease. Media coverage prompted many people to grossly overestimate familial cancer risk. When a nationwide mammography screening program was built in Germany in 2005, KID staff answered many questions concerning the availability and accuracy of this examination method and the radiation exposure associated with it.

All in all, however, questions relating to therapies have prevailed in the course of those 25 years. Thus, the breast cancer drug Herceptin is an example of a very frequent topic, says Brigitte Kukla: "Since this drug was launched on the market, there has been a great need for explanation. Why is it not suitable for every patient? Why can it only be prescribed after prior special examination of a tumor sample? We use Herceptin as an example for explaining the principle of personalized medicine."

But the multitude of options demands many decisions from affected women. "Patients are usually well informed by their doctors, but they often feel left alone with all that information. A

detailed conversation with KID staff or individually tailored information via e-mail helps them to find a good solution for themselves,” says Brigitte Kukla.

The German Cancer Research Center (Deutsches Krebsforschungszentrum, DKFZ), employing over 2,500 staff members, is the largest biomedical research institute in Germany. More than 1,000 scientists are working to investigate the mechanisms of cancer development, identify cancer risk factors and develop new strategies for better cancer prevention, more precise diagnosis and effective treatment of cancer patients. In addition, the staff of the Cancer Information Service (KID) provides information about this widespread disease for patients, their families, and the general public. DKFZ is funded by the German Federal Ministry of Education and Research (90%) and the State of Baden-Wuerttemberg (10%) and is a member of the Helmholtz Association of National Research Centers.

Dr. Stefanie Seltmann
Head of Press and Public Relations
German Cancer Research Center
Im Neuenheimer Feld 280
D-69120 Heidelberg
T: +49 6221 42 2854
F: +49 6221 42 2968
presse@dkfz.de