

# ACCESS Cancerlink Resource List

## INTRODUCTION

The first question of anyone anywhere looking for information on cancer is “where do I start?” There is a bewildering amount of information available. This list contains a selection of the most reputable, up-to-date resources to simplify your search. Included are recommendations from professionals in the field and cancer survivors.

You are invited to send us your comments on the usefulness of these resources and also to contribute suggestions of resources you have found particularly helpful.

e-mail: [cancerlink@icconnections.org](mailto:cancerlink@icconnections.org)

## DUTCH ORGANIZATIONS (web links are to English-language pages)

- **Childhood Cancer Parent Organisation (VOKK):**

<http://vokk.nl/index.cfm?fuseAction=dspEnglish>

VOKK is a national organization for parents of children with cancer. Members also include grandparents and guardians of cured or deceased children, siblings and long-term survivors. The aim is to improve the quality of life of children and families affected by childhood cancer by providing support, information and advocacy.

- **Dr LeShan Stichting:** [www.leshan.nl/index.php?page=3&sub=76](http://www.leshan.nl/index.php?page=3&sub=76)

Located in the Leiden area, the Dr Le Shan Foundation provides psychosocial support for people with cancer and their next of kin.

- **Huisman Haar Totaal:** [www.huismanhaartotaal.nl](http://www.huismanhaartotaal.nl) (website in Dutch)

Located on the Frederik Hendriklaan in The Hague, this company provides solutions for those coping with hair loss associated with cancer treatment. It is a member of the NVHO, which guarantees the professionalism of its services.

- **Integraal Kankercentrum Netherland (IKNL):** [www.oncoline.nl/index.php?language=en](http://www.oncoline.nl/index.php?language=en)

Cancer care in the Netherlands is organized in a network of 7 comprehensive cancer centers, which are partnerships between health professionals and cancer and palliative-care institutions. This website has an extensive English section.

- **KWF Kankerbestrijding (Dutch Cancer Society):**

<http://dcs.kwfkankerbestrijding.nl/Pages/Home.aspx>

The goals of the Dutch Cancer Society are less cancer, more cure and better quality of life for cancer patients. The society raises funds for cancer research and patient organizations, provides information and promotes public awareness of cancer-related issues. It also operates a Cancer Helpline. The website has a section in English.

Cancer Helpline: 0800 022 6622.

- **Lifeline:** [www.inspirecoaching.org](http://www.inspirecoaching.org)

Lifeline is an English-language cancer-support group based in the Leidschendam area. It was set up by Christine Miljkovic, who was diagnosed with breast cancer in 2008 while living in Singapore. Christine, a qualified life coach, joined the local support group and learned first-hand the benefit of being with people who were going through similar experiences.

Through Lifeline, she aims to provide a positive and fun environment to enable cancer patients to move on during and after treatment. The group meets monthly and members support each other in between.

Contact Christine by phone: 06 1378 4882 or e-mail: [lifecoachchris@hotmail.com](mailto:lifecoachchris@hotmail.com)

- **Oncoline:** [www.oncoline.nl/index.php?language=en](http://www.oncoline.nl/index.php?language=en)

Oncoline is a website designed for the consultation of nation-wide guidelines for the field of oncology and palliative care in the Netherlands. The English section contains translated multidisciplinary guidelines for diagnosis and treatment of patients with a specific cancer and also guidelines for provision of supportive care.

- **Palliatieve Zorg Amsterdam Helpdesk**

This is available 24 hours/day, 7 days a week. For information on guidelines for palliative care in the Netherlands see [www.oncoline.nl/index.php?language=en](http://www.oncoline.nl/index.php?language=en)

Helpdesk: 0900 202 1745

- **Puysseutut:** <http://puysseutut.org>

Registered as a Dutch charity but located in France, Puysseutut is a nonprofit retreat center where people who have or have had cancer can go to rest and unwind, benefit from complementary treatments, enjoy healing food, and enter purposefully into activities that can bring lasting inner peace, focus, and changes in life-style and life goals.

## **DUTCH HOSPITALS with information available in English**

- **Antoni van Leeuwenhoek, Amsterdam:** [www.nki.nl](http://www.nki.nl)
- **AZM Maastricht:** [www.english.azm.nl](http://www.english.azm.nl)
- **Bronovo Hospital, Den Haag:** [www.bronovo.nl](http://www.bronovo.nl)
- **Erasmus Medical Center Rotterdam:** [www.erasmusmc.nl/?lang=en](http://www.erasmusmc.nl/?lang=en)
- **Haaglanden Medical Center, Den Haag:** [www.mchaaglanden.nl](http://www.mchaaglanden.nl)
- **LU Medical Center Leiden:** [www.lumc.nl/home/?setlanguage=English&setcountry=en](http://www.lumc.nl/home/?setlanguage=English&setcountry=en)
- **UMC Groningen:** [www.umcg.nl/EN/corporate/pages/default.aspx](http://www.umcg.nl/EN/corporate/pages/default.aspx)
- **VU Medical Center Amsterdam:** [www.vumc.com/patientcare](http://www.vumc.com/patientcare)

## **INTEGRATIVE CANCER CARE**

Integrative Cancer Care (IC) refers to care incorporating both mainstream medicine and complementary therapies. Recognizing that a cancer diagnosis has an impact on individuals at several levels, IC is a holistic model of care that addresses biological, psychological, social and spiritual needs. While there is movement within mainstream medical communities towards adopting an IC model, it is far from being the norm. The aim in the provision of IC resources is to enable individuals make informed treatment choices and to facilitate access to complementary services.

Terminology is a source of confusion in the area of IC. The terms “alternative” and “complementary” are often used indiscriminately to describe non-medical interventions and are together referred to as “CAM” therapies. From the medical perspective “alternative” is associated with therapies used without consultation with or the knowledge of the medical care provider, while “complementary” implies a

dialogue with the medical care provider about its use. The preferred term is “complementary,” which refers to non-mainstream therapies that the medical profession considers to be safe and beneficial to the patient.

- **Annie Appleseed Project:** [www.annieappleseedproject.org](http://www.annieappleseedproject.org)

The Annie Appleseed Project is a US-based, volunteer, non-profit organization, providing information, education, advocacy, and awareness for people with cancer and their family and friends who are interested in complementary or alternative medicine and natural therapies from a patient's perspective.

This comprehensive website is like an encyclopedia with a huge number of links accessing good information—the basis for making healthy decisions about coping with cancer.

- **CAM-Cancer:** [www.cam-cancer.org](http://www.cam-cancer.org)

“CAM-Cancer” is the name of a project entitled "Concerted Action for Complementary and Alternative Medicine Assessment in the Cancer Field." Originally funded by the European Commission, it is now hosted by the National Information Center for Complementary and Alternative Medicine (NIFAB) at the University of Tromsø, Norway.

The aim of CAM-Cancer is to provide reliable information on complementary and alternative cancer treatments, which is presented as CAM summaries: peer-reviewed evidence-based articles synthesizing the best available research on CAM interventions.

- **Memorial Sloan-Kettering Cancer Center (MSKCC):** [www.mskcc.org](http://www.mskcc.org)

The Memorial Sloan-Kettering Cancer Center is a world-renowned center of excellence in cancer treatment. The website provides the best available information on a wide variety of cancers and treatments.

MSKCC has also pioneered the development of an Integrative approach to cancer care, where complementary treatments are used alongside mainstream approaches. Complementary therapies such as touch, mind-body, acupuncture, nutrition, physical activity and fitness, and dietary supplements are not substitutes for mainstream medical care. However, when used in combination with medical treatment, they can help alleviate stress, reduce pain and anxiety, manage physical and emotional symptoms, and enhance quality of life. The Integrative Care Service at MSKCC also funds and conducts clinical trials on the effectiveness and safety of new CAM treatments.

- **Penny Brohn Cancer Care Center (Bristol Center):** [www.pennybrohncancercare.org](http://www.pennybrohncancercare.org)

The Penny Brohn Cancer Care Center, formerly known as the Bristol Center, led the way in developing a holistic approach to cancer care in the UK.

The center, which is a registered charity, provides a range of complementary services and also offers retreats. An information pack (which can be downloaded from the website) includes the Bristol Approach to healthy eating, supplements and natural treatments to cope with the side effects of cancer treatments.

- **Reliable Cancer Therapies (RCT):** [www.reliablecancertherapies.com](http://www.reliablecancertherapies.com)

Reliable Cancer Therapies is a European-based non-profit organization that provides research-based information on cancer therapies. The information on the website is presented in English, French, Dutch and Spanish and will empower individuals to play an active role in making integrative treatment choices, including the possibility of participating in clinical trials.

The objective is to expand reliable treatment options for cancer using a dual approach. First, it provides patients and healthcare providers with rigorously assessed and comprehensible information on both conventional and non-conventional cancer treatments. Second, it provides funding for the development of potentially beneficial therapies, including trials less likely to be funded by pharmaceutical companies.

## OTHER SOURCES OF INFORMATION

- **AMOENA:** [www.amoena.co.uk](http://www.amoena.co.uk)

Amoena provides products and services to enhance quality of life following breast surgery. The website has an online shop.

- **Breast Cancer Care:** [www.breastcancercare.org.uk](http://www.breastcancercare.org.uk)

Breast Cancer Care offers extensive information and downloadable publications from the website. There are also discussion forums, opportunities to speak to nurses and a forum specifically for younger women.

- **International Strategic Cancer Alliance (ISCA):** [www.is-canceralliance.com](http://www.is-canceralliance.com)

The objective of the International Strategic Cancer Alliance is to help patients to connect with medical professionals who can integrate a vast array of synergistic therapies into individually tailored (boutique) treatment programs.

Currently focused on newly diagnosed prostate- and breast-cancer patients, ISCA helps patients navigate the medical world, while consulting with top experts and researching the best available protocols for each individual—designing a customized approach through coordinated efforts.

ISCA can also organize all of an individual's medical records into an international medical file, which facilitates access to medical information by medical specialists anywhere in the world and, thus, facilitates the international cooperation of specialists in a treatment plan. Another useful feature on the website is a downloadable tutorial in how to research abstracts and scientific journals for best practice in the treatment of specific cancers.

- **Journey Forward:** [www.journeyforward.org](http://www.journeyforward.org)

Care after treatment is an essential but often missing step in a patient's cancer journey. This website provides guidance on what to look for, including a downloadable toolkit that can be used to develop an aftercare plan. While this is oriented towards the US, it is very useful in facilitating clarity in communicating needs anywhere.

- **Lobstar:** [www.lobstar.nl/en.html](http://www.lobstar.nl/en.html)

Aimed at women who “still want to look good” after having a mastectomy, Lobstar is a Dutch company that “designs and produces fashionable and proper fitting clothing for women with an asymmetrical body.” Information is available on the website in Dutch, English and German.

- **Macmillan Cancer Support:** [www.macmillan.org.uk](http://www.macmillan.org.uk)

Macmillan is a UK-based cancer-care and -support charity, offering high-quality, up-to-date information on a wide range of cancers and treatments. It is also possible to access support from professionals or fellow cancer patients via the online community.

- **Maggie Centers:** [www.maggiecenters.org](http://www.maggiecenters.org)

Maggie Centers provide social, psychological and emotional support to cancer patients and their family. They are located mainly in the UK but also have centers in Hong Kong and Barcelona. There is also an online center that offers access to information, professional support and the opportunity to share experiences with someone in a similar situation.

- **Mesothelioma:**

Asbestos exposure has been proven to result in a wide range of health conditions, including mesothelioma, a deadly cancer that attacks the linings of the lungs, heart, or abdomen.

The Mesothelioma Center ([www.asbestos.com](http://www.asbestos.com)) is an up-to-date resource for all things related to asbestos and mesothelioma, ranging from [the disease](#) to [mesothelioma statistics](#).

See also [Mesothelioma Resource Online](#), the [Mesothelioma Cancer Alliance](#), [Mesothelioma Prognosis](#), and the [Mesothelioma Association](#).

- **National Coalition for Cancer Survivorship (NCCS):** [www.cancersurvivorship.org](http://www.cancersurvivorship.org)

The NCCS advocates quality cancer care and empowerment through accurate and credible information. A key feature of this website is access to the award-winning Cancer Survival Toolbox®, a free, downloadable, self-learning audio program that has been developed by leading cancer organizations. The objective is to help people develop important skills to better meet and understand the challenges of their illness from diagnosis onwards. It contains a set of basic skills to help navigate diagnosis, as well as special topics on key issues faced by people with cancer. It is available in a number of languages, including Chinese.

- **Prostate Cancer Research Institute (PCRI):** [www.prostate-cancer.org/pcricms](http://www.prostate-cancer.org/pcricms)

With the motto “Helping Men to Know Their Options,” the Prostate Cancer Research Institute provides a newsletter, information, helpline and resources support groups, clinical trials and a decision aide to provide an in-depth roadmap that will empower men to locate and use information that is pertinent to their situation.

- **The Haven:** [www.haven.co.uk](http://www.haven.co.uk)

The Haven provides specialist breast-cancer support free of charge in a number of centers in the UK and offers an online outreach service, called Haven at Home, to people who cannot go to the centers. This contains useful downloads such as stress-management techniques and information on supporting a loved one with breast cancer.

- **US National Cancer Institute:** [www.cancer.gov](http://www.cancer.gov)

The website of the US National Cancer Institute is one of the most comprehensive sources of reliable information in the field of cancer. In both English and Spanish, it provides answers to basic questions about cancer, detailed information on common cancers, A-Z of all cancer types, and access to the results of clinical trial.

- **WebMD:** [www.webmd.com](http://www.webmd.com)

This is a complete medical encyclopedia, which includes chat rooms and new developments in care.

## BOOKS

- **“Journeys with the Cancer Conqueror” by Greg Anderson (Andrews McMeel Publishing, 1999)**

Greg Anderson is a survivor of metastatic lung cancer. In 1984 he was told that he had 30 days to live. In this book he shares what he has learned on his journey of conquering cancer. His message is that the body's healing capacity is directly linked to mental and emotional well-being. By embracing healthy beliefs and attitudes, learning to effectively resolve emotional distress and moving in the direction of greater joy and gratitude, even while living with cancer, we can harness our healing potential.

Website: <http://greganderson.org>

- **“Life Over Cancer” by Keith Block (Bantam, 2009)**

Keith Block is at the global vanguard of innovative cancer care. As medical director of the Block Center for Integrative Cancer Treatment in Evanston, Illinois, he has treated thousands of patients who have lived long full lives beyond their original prognosis. In this very readable book, he has distilled almost 30 years of experience to give a systematic, research-based plan for developing the physical and emotional vitality required to meet the demands of treatment and recovery.

Website: [www.lifeovercancer.com](http://www.lifeovercancer.com)

- **“The Complete Guide to Complementary Therapies in Cancer Care” by Barrie R. Cassileth (World Scientific, Nov, 2011)**

Barrie R. Cassileth is founder and director of the Integrative Medicine Department at the renowned Memorial Sloan Kettering Cancer Center in New York. This now serves as an international prototype for the development of integrative cancer care. As researcher, educator and director, she has worked in integrative and psychosocial aspects of cancer care for over 30 years. This book presents a comprehensive guide to complementary therapies, with information about safety and the possible benefits of treatments as well as caveats against indiscriminate use of others.

- **“The China Study” by T. Colin Campbell and Thomas M. Campbell (Benbella, 2006)**

Colin Campbell is regarded as one of the foremost experts in the field of nutrition. In “The China Study,” he and his son Tom present the history of the struggle to understand and explain the vital connection between our health and what we eat. Based on hard-core scientific research, they illuminate the link between nutrition and cancer in an accessible and engaging way. It will convince you of the importance of nutrition in any cancer-prevention or cancer-treatment strategy.

Website: <http://thechinastudy.com>

- **“Full Catastrophe Living” by Jon Kabat-Zinn (Piatcus, 2008)**

This book is based on Kabat-Zinn's highly successful stress-management program developed at the University of Massachusetts Medical Center, where he uses mindfulness, a form of meditation, to help individuals cope with stress, anxiety, pain and illness. This is very readable and a compelling guide to using mindfulness to manage both the physical and emotional effects of cancer.

- **“The Prostate Book” by Peter Scardino, (Avery, 2005)**

Widely regarded as one of the finest prostate surgeons, Dr. Scardino provides an essential resource for men with this book. He unveils the mysteries of this confusing and often misunderstood organ and provides thoroughly researched but easy to understand information on prostate function and malfunction and the treatment of prostate problems, especially cancer.

- **“Anticancer: A New Way of Life” by David Servan-Schreiber (Penguin Books, 2009)**

When David Servan-Schreiber, doctor and scientific researcher, was diagnosed with brain cancer, his life changed. Confronting what medicine knows about the illness and the little-known workings of the body's natural cancer-fighting capability, he found himself on a 15-year journey from illness and relapse to scientific exploration and, finally, health.

Draws on both conventional and alternative ways to slow and prevent cancer, this book combines his memoir with concise explanations of what helps cancer cells survive and what inhibits them. It is a moving story of a doctor's inner and outer search for balance and is compelling in its proposal that cancer cells lie dormant in all of us and that we all must care for the terrain in which they exist.

Website: [www.anticancerbook.com](http://www.anticancerbook.com)