

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

DUTCH ORGANISATIONS

- **KWF Kankerbestrijding (Dutch Cancer Society):** www.kwfkankerbestrijding.nl

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: 0800-0226622.

- **Integraal Kankercentrum Netherland:** www.ikcnet.nl

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. However, this can be difficult to locate. On home page click on any of the underlined words in the introductory paragraph. This will open a new home page, which has a list of options across the top. The English section is accessed by clicking on “Comprehensive Cancer Centers”.

- **Dutch Childhood Cancer Parent Organisation (VOKK):** www.vokk.nl

VOKK is a national organization of 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.

- **Oncoline:** www.oncoline.nl

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.

- **Dr LeShan Stichting:** www.leshan.nl

Located in the Leiden area, the Dr Le Shan Foundation provides psychosocial support for people with cancer and their next-of-kin. There is an English section on the website which is accessed by clicking on “Begleiding” and then on the English tab in the menu that appears.

- **Palliative care:**

Helpdesk Palliatieve Zorg Amsterdam: 0900-2021745

This is available 24h, 7 days per week.

For information on guidelines for palliative care in the Netherlands see www.oncoline.nl

- **Huisman Haar Totaal:** www.huismanhaartotaal.nl

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.

- **Lifeline:** www.inspirecoaching.org

Lifeline is an English speaking 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 firsthand the benefit of being with people who were going through similar experience.

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, 0613784882, or via e-mail, lifecoachchris@hotmail.com.

DUTCH HOSPITALS (with information available in English)

- **Antoni van Leeuwenhoek, Amsterdam:** www.nki.nl
- **VU Medical Center Amsterdam:** www.vumc.nl
- **Bronovo Hospital, Den Haag:** www.bronovo.nl
- **Haaglanden Medical Center, Den Haag:** www.mchaaglanden.nl
- **UMC Groningen:** www.umcg.nl
- **LU Medical Center Leiden:** www.lumc.nl
- **AZM Maastricht:** www.azm.nl
- **Erasmus Medical Center Rotterdam:** www.erasmusmc.nl

NON-DUTCH/INTERNATIONAL ORGANISATIONS

- www.webmd.com:
This is a complete medical encyclopedia which includes new developments in care and chat rooms.
- **US National Cancer Institute:** www.cancer.gov

The website of the National Cancer Institute of the US 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 clinical trial results into treatments.

- **Macmillan Cancer Support:** 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 treatment. It is also possible to access support from professionals or fellow cancer patients via the online community.

- **National Coalition for Cancer Survivorship (NCCS):**

www.cancersurvivorship.org

The NCCS advocates for 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, 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. The program contains a set of basic skills to help navigate a diagnosis and special topics on key issues faced by people with cancer. It is available in a number of languages including Chinese.

- **International Strategic Cancer Alliance:** www.is-canceralliance.com

The objective of International Strategic Cancer Alliance (ISCA) is to facilitate patients to connect with medical expertise 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 help patients navigate the medical world while consulting with top experts and researching the best available protocols for each individual. Through a coordinated effort, a customized approach is designed

ISCA can also organize all of an individual's medical records into an International Medical File. This facilitates access to medical information by medical specialists anywhere and thus the international co-operation 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 treatment of specific cancers.

- **Journey Forward:** 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 tool kit which 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.

- **Maggie Centers:** www.maggiencenters.org

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

- **Breast Cancer Care:** www.breastcancercare.org.uk

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

- **The Haven:** www.haven.co.uk

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

- **AMOENA:** www.amoena.co.uk

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

INTEGRATIVE CANCER CARE

Integrative Cancer Care (IC) refers to care incorporating both mainstream medicine and complementary therapies. It recognizes that a cancer diagnosis impacts on individuals at several levels. Integrative Care is a holistic model of care addressing 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 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 or knowledge of medical care provider while complementary implies a dialogue about use. The preferred term is now complementary and refers to non-mainstream therapies which the medical profession considers to be safe and deliver benefit to the patient.

- **Memorial Sloan-Kettering Cancer Center:** www.mskcc.org

Memorial Sloan-Kettering Cancer Center (MSKCC), New York, is a world renowned center of excellence in cancer treatment. The website provides the best available information on 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. 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 effectiveness and safety of new CAM treatments.

- **Penny Brohn Cancer Care Center (Bristol Center):**
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 can be downloaded from the

website which includes the Bristol approach to health eating, supplements and natural treatments to cope with side effects of cancer treatments.

- **CAM-Cancer:** 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" (CAM-Cancer). Originally funded by the European Commission (EC) 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. This is presented as CAM summaries; peer-reviewed evidence-based articles synthesizing the best available research on CAM interventions.

- **Annie Appleseed Project:** 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 (CAM) 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.

- **Reliable Cancer Therapies (RCT)**
www.reliablecancertherapies.com

Reliable Cancer Therapies (RCT) is a European based non-profit organization providing research-based information on cancer therapies and selectively funding the development of promising therapies. The information on the website is presented in English, French, Dutch and Spanish.

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

The information on the website will empower individuals to play an active role in making integrative treatment choices including the possibility of participating in clinical trials.

Books:

1. "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.

2. "Life Over Cancer" by Keith Block (Bantam, 2009)

Dr 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. See also website: www.lifeovercancer.com

3. "The Complete Guide to Complementary Therapies in Cancer Care" by Barrie R. Cassileth (World Scientific, Nov, 2011)

Dr 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 possible benefits of treatments as well as caveats against indiscriminate use of others.

4. "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 he illuminates the link between nutrition and cancer in an accessible and engaging way.

Read it and be convinced of the importance of attention to nutrition in any cancer prevention or cancer treatment strategy.

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

This is based on Kabat-Zinn's highly successful stress management programme developed at the University of Massachusetts Medical Centre, 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.

6. “The Prostate Book” by Dr Peter Scardino, (Avery, 2005)

Dr Scardino is widely regarded as one of the finest prostate surgeons. This book is an essential resource for men to unveil the mysteries of this confusing and often mis-understood organ. It provides thoroughly researched but easy to understand information on prostate function and malfunction and treatment of prostate problems, especially cancer.

7. “Anticancer: A New Way of Life” by Dr 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.

The book combines memoir and concise explanations of what makes cancer cells survive and what inhibits them and draws on both conventional and alternative ways to slow and prevent cancer. It is a moving story of a doctor's inner and outer search for balance and 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.

See website www.anticancerbook.com

