# Women's Cancers

Edited by Alison Keen & Elaine Lennan



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Edited by

Alison Keen and Elaine Lennan

Foreword by Professor Stan Kaye

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# Foreword

The cancers which specifically affect women are breast and gynaecological cancers, and in both cases much has changed over the past 5–10 years. Scientists now have a much better understanding of the basic mechanisms causing these cancers to develop, and with this has come the development of new and promising forms of treatment, called targeted therapy. Treatment results are beginning to improve, but still have some way to go. Patients with breast and gynaecological cancers, as well as their families, have to contend with a large number of difficult and challenging issues; to help them to do this it is vital that their carers are fully informed in all areas.

This textbook is designed to meet those needs, and the editors and authors are to be congratulated on providing a comprehensive, highly readable and up-to-date resource, suitable for a wide range of health care professionals, as well as patients and families. The editors have assembled an experienced team of experts from across the relevant disciplines, and the public can be assured that this is indeed an authoritative piece of work. No doubt the patients' experiences described throughout the book will strike a chord with many, and the perspective which this provides epitomizes the holistic approach of the editors. As treatments are improving, more women are living with cancer than ever before; this continues to present a wide range of problems that need to be addressed, and these are comprehensively covered in several chapters.

In recent years, a major change in the public's attitude to cancer has taken place. Formerly a taboo subject, it is now discussed widely and openly in a wide range of situations. For various reasons, women's cancers generally receive most attention, and in an era of ever-increasing dissemination of knowledge, it is all the more important that information that is available is accurate and provided in the appropriate context. With this in mind, this textbook is extremely timely and most welcome.

Professor Stan Kaye
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# Introduction

This book is dedicated to the women that the authors have met over many years in their roles as Clinical Nurse Specialist in Gynaecological Cancer and Consultant Nurse. Whilst much of the understanding of the physiological and psychological effects of women's cancer has been gained through the study of theory, the most complete and in-depth understanding comes from sitting alongside women at diagnosis, through various treatments, and in the anxiety-ridden periods between 'follow-up' appointments. Women and their families have trusted us enough to share their fears, celebrated the success of treatments and discussed intimate issues that often go unsaid in the course of 'normal' life. The varying ways in which people react and cope with the often seemingly unbearable stresses of living with cancer never cease to astound and amaze. Whilst advanced communication skills training, years of nursing practice, and life experience, offer a framework for supporting and helping people whose lives are suddenly in crisis and surrounded by uncertainty, these are not the key elements in enabling a therapeutic relationship. It is the authors' philosophy that the relationship is a two-way experience based on mutual respect, trust and kindness. Much of the book, whilst grounded in theory, is an exploration of the experience of living with cancer, based on years of profound and privileged communication. Women known to the authors, who have offered to contribute to the book, have given many of the quotes, have written their accounts and stories, and some of the accounts are taken from the authors' research. All contributors have kindly given permission for their words to be published.

The aim of the book is to provide a comprehensive and meaningful picture of women's cancers, including epidemiology, histopathology, normal anatomy and physiology, staging, genetic predisposition, sexual function, fertility, the treatment and management of women's cancers, survivorship, and palliative care. The readership who are likely to gain most from the text will be any health care professional who is working in a cancer care setting with particular relevance to women's cancers, or health care workers in community practice, who wish to update. The authors are an eclectic mix of carefully selected specialists in their field, who have researched and written from current clinical experience and have demonstrated their motivation and expertise by their contribution. The book demonstrates their wealth of experience and expertise and the chapters reflect this well.

Chapter 1 is an exploration of the history of women in relation to health and cancer. The following Chapter 2 on epidemiology gives a comprehensive account of cancer prevalence. Chapter 3 is a comprehensive section on histopathology and staging of breast and

gynaecological cancers, and includes a section on the importance of the histopathologist in the Multi-disciplinary Cancer Team. It outlines the staging frameworks used for specific cancers and the relationship between staging and prognosis. The significance of tumour markers is detailed in Chapter 4, with the meaning of markers to women highlighted by a patient. Chapter 5 on genetics covers susceptibility to female cancers and the process of genetic testing, inherited predisposition and the psychological impact of genetics testing. Strategies to manage increased risk are discussed and illustrated succinctly by a woman's own story. This will become increasingly important over the next decade. In Chapter 6, lifestyle and prevention provides a detailed account of risk factors associated with cancer development. It examines lifestyle choices and the public health messages aimed at public awareness. Site specific Chapters 7 to 13 also include risk factors, presentation and incidence, and discuss the importance of histopathological staging in determining the treatment plan. Future research and therapies are summarised at the conclusion of each of these chapters. The impact of cancer and treatments on fertility is comprehensively described in Chapter 14, which includes modern fertility preservation techniques and the effect of pregnancy on cancer. A book on women's cancers could not be complete without Chapter 15, providing information on normal sexual function and how cancer and treatment affects these. Assessment tools and therapeutic interventions are also included. Chapter 16, on rehabilitation and survivorship, covers aspects of living beyond cancer treatments and the many policies and strategies available to patients and carers to enable self management and support. Palliative care is the obvious choice for the concluding Chapter 17, which explains the relevant organisational aspects and explores the many facets of total care, including psychological, social, cultural and spiritual care. The section on symptom control gives guidance on common cancer related symptoms, with particular reference to breast and gynaecological cancer.

The impact of a cancer diagnosis on a woman and her loved ones cannot be underestimated. Relationships change and there is often the need to re-evaluate interactions with family and friends. The challenges to contend with include adapting to the diagnosis, coping with the effects of treatment, adjusting from active treatment to follow-up, and living with the uncertainty of recurrence. However, given the right amount of care and support can mean that the patient and her family can cope with the total disruption in their lives. The health care professionals' holistic aim should be to help people to manage their distress, keep them well informed, provide supportive care, guide and help them through the health care system, provide specialist support in symptom control, nutritional help, psychological care, and practical support to maintain independence. Support groups, patient advocacy agencies, patients' own voices and contribution to health boards and health care teams and cancer charities are engaging with health care providers to enable collaboration in the planning of future cancer care services.

A woman with ovarian cancer observed:

> *One of the greatest struggles in the battle against cancer is to realise that 'the essential self' endures. Despite so much else getting in the way – so many fears, so much discomfort and pain, so many reasons to give up. Yet there are the reasons for keeping going: the hope, the love of family and friends, the support of caregivers, and the desire to live and feel like myself again. In the midst of it all it is easy to feel lost and*

*to be identified as a number, an operation, and CT images. The bald woman looking back at me in the mirror was alien, a constant reminder of the losses that I had experienced.*

To enable people to regain a sense of self is one of the many challenges of cancer care; of course, the means of achieving this are complex. But a good starting point is to face each individual new patient as an opportunity in 'getting it right'; to give time and respect, to listen and inform and to treat with unconditional positive regard. At the end of treatment, carers need to ensure that care continues by providing services that offer rehabilitation and survivorship and by having awareness that the end of treatment is often a new beginning.

Alison Keen

# Contents

Chapter 1

# The History of Women in Relation to Health and Cancer

Victoria Harmer and Maureen Royston-Lee

## Women and health

Throughout history, women have been considered the weaker sex. Health surveys repeatedly illustrate that females have higher rates of illness, disability days and health service utilization than do males (Verbrugge 1979). This is in spite of women giving priority to fulfilling their work responsibilities over their discomfort (Amin and Bentley 2002); indeed those with employment or who have an ill child are significantly less likely to cut down on their activity because of symptoms (Woods and Hulka 1979).

## Women and mental illness

Women are commonly believed to be more susceptible to emotional breakdowns and mental illness, as they are deemed to be not as psychologically durable as men.

The notion of nymphomania developed during the second half of the seventeenth century. A third of all patients in Victorian asylums apparently suffered from this condition. Described as an irresistible desire for sexual intercourse and a female pathology of over-stimulated genitals, it was associated with a loss of sanity. It was believed that without treatment these women would become raving maniacs, robbed of their minds. Cures for nymphomania included separation from men, induced vomiting, cold douches over the head, bloodletting, warm douches over the breasts, solitary confinement, leeches, straight-jackets, bland diets and occasionally clitorectomies.

Spinsters and lesbians were also considered a threat to society during the nineteenth century. Any women, who went outside the social norm and made their own decisions, were thought to be mentally ill, as doctors claimed being without male interaction over the long term would result in irritability, anaemia, tiredness and fussing. Again women were admitted to the asylum or forced into marriage, as it was assumed their condition could be cured by repeated sexual interaction with men.

During the mid-nineteenth century came the idea of the 'wandering womb'. Madness was associated with menstruation, pregnancy and the menopause, and the womb was

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thought to wander throughout the body acting like an enormous sponge, sucking life from vulnerable women (Ussher 1991). Thus women became more synonymous with madness and generally thought to be emotional and unstable.

In developed countries such as Britain, women are more likely than men to be admitted to hospital for psychiatric treatment, and both first-time and total admissions to psychiatric hospitals are dominated by women (Miles 1988; DH 1995; Payne 1995). Women are also more likely to be treated by general practitioners and community psychiatric teams for mental health problems. Whilst women and men are equally represented amongst admissions for schizophrenia, women are twice as likely to be admitted due to depression and anxiety (Payne 1995; DH 1995). Older women and women from minority ethnic groups are the most likely to be given a psychiatric diagnosis and to receive treatment for that condition (Doyal 1998).

## Eating disorders

Anorexia is an eating disorder and a mental health condition that usually develops over time, most commonly starting in the mid-teens. In teenagers and young adults, the condition affects about 1 in 250 females and 1 in 2000 males (DH 2008a).

Anorexia was officially recognised as a disease in 1873 (Wiederman 1996), and flourished throughout the nineteenth century as women wanted to accentuate their femininity. The physical and spiritual ideal of anorexia became a status symbol for women, showing them to be middle to upper class, as working-class women could not afford to become anorexic as they needed to eat in order to work. Once more, treatment was by admission to an asylum, where the women could rest and be excessively fed.

## Breast cancer in ancient Egypt and Greece

Breast cancer was first 'discovered' by the ancient Egyptians over 3500 years ago. In 460 BC, Hippocrates, the father of Western medicine, described breast cancer as a disease of one of the 'humours' in the body. There were four 'humours', blood, phlegm, yellow bile and black bile. Hippocrates suggested that cancer was a result of an excess of black bile or 'melanchole'. The breast, if left untreated, would become black and hard and would eventually break open and black fluid would ooze from it.

In 200 AD, Hippocrates' successor, Galen, also described cancer in terms of 'excessive black bile', but he felt that some tumours were more serious than others. The treatment available for breast cancer at the time of Galen included opium, castor oil, liquorice and sulphur. Surgery was not an option as it was felt that the cancer would reappear at the site of the surgery or elsewhere in the body (Garrison 1966).

For the next 2000 years, physicians considered breast cancer as a systemic disease, as the dark bile was thought to travel around the entire body, causing tumours in other organs.

It was not until 1680 that a French physician, Francois de la Boe Sylvius, began to challenge the notion of breast cancer as a 'humoural' disease. He felt that cancer was

caused by a chemical process that resulted in lymphatic fluids becoming acrid instead of acidic (Olson 2002).

An interesting hypothesis was put forward by Bernardino Ramazzini in 1713, who noted the higher than normal occurrence of breast cancer in nuns, and concluded that the origin of breast cancer was sexual. The absence of sexual activity in nuns was thought to affect the reproductive organs, including the breast, which started to decay resulting in cancer (Olson 2002)!

There were of course other theories that did not involve sex, including depression, which constricted the blood vessels and trapped coagulated blood, again resulting in breast cancer. Another theory postulated that the cause lay in a sedentary life, causing bodily fluids to become sluggish.

## The eighteenth century onwards: breast cancer and surgery

There was no shortage of theories but there was a major shift in opinion amongst eighteenth-century physicians who began to see breast cancer as a more localised disease. The implications of this were enormous, as it meant that surgery now had a significant part to play in the treatment. In 1757, Henri Le Dran, argued that surgery could actually cure breast cancer, provided that it also included the removal of the infected axillary lymph nodes.

By the mid-nineteenth century, breast cancer was accepted as a localised disease and surgery was the treatment of choice. This view was enhanced by the vast improvements in anaesthesia, antiseptic procedures, blood transfusion and the public trust in medicine. William Halstead, an American surgeon, emerged as the leader in the field of breast surgery, when he pioneered the Halstead Mastectomy that became the 'gold standard' for the next 100 years (Olson 2002). This was a radical mastectomy that involved removal of the breast, axillary nodes and both chest muscles in a single block procedure. Halstead performed hundreds of radical mastectomies but the procedure was not without severe side effects. Women had to cope with a poor cosmetic result, including a deformed chest wall and hollow areas under the collar bone, chronic pain and lymphoedema due to the removal of the lymph glands. Halstead felt that this was a small price to pay, as the women's average age was 'nearly fifty-five years and they are no longer active members of society' (Olson 2002).

## Twentieth-century breast surgery

A major advancement in the treatment of breast cancer was made by the Scottish surgeon, George Beatson, in 1895. He discovered that when he removed the ovaries from his patients, their breast cancers shrunk significantly. This resulted in many surgeons carrying out oophorectomy routinely, which resulted in debilitating side effects, as they were unaware that not all breast tumours had oestrogen receptors.

Fast forward to 1976, when Bernard Fisher published results indicating that breast conserving surgery, followed by radiotherapy or chemotherapy, were just as effective as radical mastectomy, and often even more so (Hellman 1993).

## Gynaecological cancers

In the nineteenth century, cancer was seen predominately as a 'woman's disease'. This notion was based on the prevalence of cancer in the breast and uterus and the incidence of cancer being three times higher in women than in men (Walshe 1846).

Walshe felt that women were at greater risk of getting cancer because of their biological role in reproduction and the menopause. His contemporaries believed that problems of nutrition due to repeated pregnancies made women more prone to cancer.

By the mid-nineteenth-century, physicians began to take the view that cancer was more a systemic disease, with a hereditary component making it incurable. The hereditary issue is interesting, as it carried with it a stigma and evoked undesirable qualities that meant people's lives were adversely affected socially, economically and emotionally. There was also the notion that predisposing causes could also be acquired as well as inherited. These included temperament and immoral habits! Cervical cancer was associated with excessive sexual activity and breast cancer was associated with trauma.

The treatment of women's cancers in the first half of the nineteenth century was somewhat harsh. There was a brief period when gynaecological cancers were treated surgically by amputation of the cervix but thankfully that 'fashion', which carried a high mortality rate, was short-lived. In the second half of the nineteenth century, there was a new understanding that these cancers were more of a local disease and surgical techniques improved accordingly.

In 1896, leading obstetrician, William Japp Sinclair (1896), believed that there was a strong connection between poor social conditions and the development of cancer (Sinclair 1902). Cervical cancer was usually associated with lack of personal hygiene, venereal disease and the recurrent lacerations and infections caused by multiparity and poor obstetric care.

In the late 1880s, there was a belief that the origins of cancer existed outside the body. Germs and parasites were detected in cancer cells and this led to controversy at the time. In 1902, a general practitioner remarked that 'the loose and open arrangement of the nether garments of the majority of women would naturally favour access to the generative organs of the infective micro-organism' (Brand 1902). It would appear that the medical profession had 'it in for' women, and the vast majority of medical doctors at the time would have been men.

## Nineteenth century onwards

By the end of the nineteenth century, a new risk factor liable to cause gynaecological cancer emerged, that of unclean male genitalia (Mort 1987). The social purity movement, comprising feminists, medics and nonconformist Protestants, were involved in reshaping the nation's morals and took a view that male sexuality was a source of 'moral pollution'. There was a drive to denounce the 'double standards' of sexuality that existed between men and women. Within this context, a major public health hazard was identified, that of men's foreskins, where germs were harboured and led to cervical cancer. Doctors made a connection between the low incidence of cervical cancer, as well as syphilis and gonorrhoea, amongst the Jews (Darby 2003).