
Occupational Therapy in Oncology and Palliative Care

2nd edition

Edited by

JILL COOPER



John Wiley & Sons, Ltd

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Contributors

Helen Barrett BA (Hons), BSc (Hons), OT

Senior Occupational Therapist, The Royal Marsden NHS Foundation Trust,
Downs Road, Sutton, Surrey, UK SM2 5PT

Kathryn Boog BSc (Hons), OT

Senior Occupational Therapist, St Columba's Hospice, Boswall Road,
Edinburgh, UK EH5 3RW

Anne Bostock DipCOT, OT

Senior Occupational Therapist, Sue Ryder Care – Leckhampton Court
Hospice, Leckhampton Court, Church Road, Leckhampton, Cheltenham,
UK GL53 0QJ

Will Chegwiddden BSc OT (Hons), OT

Senior Occupational Therapist, The Royal London & St Bartholomew's NHS
Trust, London, UK E1

Jill Cooper DipCOT, DMS, OT

Head Occupational Therapist, The Royal Marsden NHS Foundation Trust,
Fulham Road, London, UK SW3 6JJ

Derek Doyle MD, OBE

Retired Consultant in Palliative Medicine, Senior Editor of The Oxford Text-
book of Palliative Medicine, Vice President and Honorary Vice Chair of the
National Council for Palliative Care

Shelley Ellis BSc (Hons), OT

Senior Occupational Therapist, Great Oaks Dean Forest Hospice and com-
munity, The Gorse, Coleford, Gloucestershire, UK GL16 8QE

Gail Eva BSc (OT)(Hons), MSc, OT

Team Leader Hospital and Community Palliative Care, Sir Michael Sobell
House Hospice, Churchill Hospital, Headington, Oxford, UK OX3 7LJ

Camilla Hawkins DipCOT, LHMC, MScOT, OT

Senior Occupational Therapist, Mildmay Hospital, London, UK E1

Gemma Lindsell BA (Hons), DipCOT, OT

Senior Occupational Therapist, The Royal Marsden NHS Foundation Trust,
Fulham Road, London, UK SW3 6JJ

Daniel Lowrie BHSc (OT), OT

Lecturer/practitioner Occupational Therapist, The Royal Marsden NHS Foundation Trust, Fulham Road, London, UK SW3 6JJ

Sara Mathewson BSc(Hons), OT

Senior Occupational Therapist in Palliative Care, Gloucester Royal Hospital NHS Foundation Trust, Great Western Road, Gloucester, UK GL1 3NN

Lilias Methven DipCOT, OT

Senior Occupational Therapist, Gloucester Royal Hospital NHS Foundation Trust, Great Western Road, Gloucester, UK GL1 3NN

Claire Tester DipCOT, PGDip, OT

Senior Occupational Therapist, Rachel House Children's Hospice, Avenue Road, Kinross, UK KY13 8FX

Julie Watterson BSc (Hons), OT

Senior Occupational Therapist, Prospect Hospice, Moormead Road, Wroughton, Swindon, Wilts, UK SN4 9BY

Foreword

The death of Dame Cicely Saunders (in July 2005), the charismatic visionary behind the Hospice Movement, brought home to many of us both the importance of what she advocated and the remarkable, worldwide acceptance of the principles of palliative care. From modest beginnings in 1967 there are now, in 2005, more than 8000 palliative care services worldwide, more than 20 academic professorial chairs, countless undergraduate and postgraduate qualifications available, and more than 300 multiprofessional research projects on the go at any one time. In the United Kingdom alone there are 217 in-patient palliative care units, 356 community palliative care services, 258 day care units and 83 hospital palliative care teams.

At the heart of each one, whatever the type of service, are the patients and their loved ones. Each hopes for cure or if cure is unrealistic, for a life worth living, a life that they and they alone can say has 'quality'. It may not be a long life, any more than it might resemble their life before their illness but, for them, it is a life worth living – a life with as little dependency on others as possible, a life without suffering, a life with smiles and happy times shared with family and friends preferably in their own homes.

Palliative care provision has burgeoned, as we have seen, but it has changed in other ways since the first edition of this book. No longer is it primarily concerned with oncology patients. Today hospital palliative care teams can expect to be invited to see patients with advanced cardiac, respiratory, neurological and even infectious conditions. No longer will most be in the far advanced stages of illness. Some may still be under their care a year or more later, still spending much of their time at home.

Oncology has changed, almost as dramatically as has palliative care. With earlier referrals, more sophisticated investigations and new drugs many malignancies can be controlled for years – not cured but controlled sufficiently for patients and carers to have every reason to talk about quality rather than quantity of life. No longer is there a false dichotomy between oncology care and palliative care as was once the case. Oncology teams now offer good palliative care and see that as part and parcel of their work. The two disciplines for whom this book is written now recognize that neither can work in isolation, that they share aims and many skills, and that they can and must work together respecting the training, the skills and the contributions of the other.

The society in which we live and work is also changing, perhaps quicker and more radically than many of us would wish. No matter how much people

say that when the time comes they would like to die at home, studies are showing that this is seldom achieved. No matter how much family doctors and community nurses would like to care for the terminally ill at home, this is becoming ever more difficult because of their workload, inadequate resources, and unsatisfactory out-of-hours cover. Cover of the chronically ill and aged is suffering. Resources for care, whatever the condition, are being directed more towards cure than long term or palliative care. 'Hard' research attracts more funding than 'soft' research into such things as feelings, spiritual needs, needs of relatives, stress of the carers and quality of life. Some would go so far as to say that since the first edition of this book we have moved back to being more interested in the pathology than in the person with that pathology, vehemently as most would deny that.

What cannot be denied is that occupational therapy has grown as a discipline and grown in importance and is certain to continue on that road. It is not an optional extra in today's care team, whether in hospital or community. Today, the occupational therapist is an indispensable, integral member of each team but the value of her/his contribution will largely rest on the adequacy of her training, her well-informed understanding of the work and contributions of other disciplines, and sensitivity to the nature of changes in our society. The challenges of this work are truly enormous but so too are the rewards.

I commend this new edition as a major contribution to better care for people at one of the most frightening times of life. No greater challenge and no greater rewards can any of us ever have than caring for those on their final, often very long and lonely, road of life.

Dr Derek Doyle
Hon. Vice Chairman National Council for Palliative Care
July 2005

Preface

The second edition of this book aims to explore further occupational therapy for persons with life-threatening and life-limiting illnesses. The most common diseases that most occupational therapists will encounter are cancer and heart disease, as well as other conditions, which are classified under the umbrella term of palliative care, such as HIV/AIDS, neurological and congenital illnesses. The fundamental principles of occupational therapy in oncology and palliative care still apply and this edition will discuss and examine treatment programmes and approaches that have been developed with evidence-based practice.

Specific solutions may still not exist for all specific problems. Individual coping mechanisms are required for people whether they have physical, psychological or psychosocial difficulties so the occupational therapist needs to refine their core and problem-solving skills and analyse each case as it arises.

Working with individuals who have cancer or are at the palliative stages of a disease involves considering their ability to survive and, if the illness is terminal, assessing how to facilitate them and their carers in achieving optimum quality of life in their remaining time. This second edition focuses on suggested occupational therapy interventions that can be adapted to suit different work settings and environments.

The first chapter revisits the basic terminology for cancer and palliative care interventions, treatments, side effects and related issues. This is followed by a discussion of the principles of occupational therapy in this clinical area, first in general terms and then with specific reference to more complex issues. Subsequent chapters discuss more specific symptoms and approaches as well as exploring the use of creativity as a psychodynamic activity and examining palliative care far more broadly, particularly in paediatrics. The examples of treatment programmes are a consensus of expert practitioners throughout the UK and are designed to be used and adapted to suit individual requirements, work settings and requirements.

This second edition aims to underpin clinical practice with evidence-based information wherever possible and should be used to support practice development and used as a workbook format. In some scenarios, the individuals receiving treatment are referred to as clients; at other times, they are referred to as patients. This depends on the health care setting.

Various political influences, particularly in the United Kingdom, have occurred since the publication of the first edition in 1997 including the NHS

Cancer Plan (DoH, 2000) and NICE Guidelines for Supportive and Palliative Care (NICE, 2004) and these continue to recognize the value of occupational therapy in this clinical area.

Jill Cooper
Royal Marsden NHS Foundation Trust

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- NICE (2004) *Improving Supportive and Palliative Care for Adults with Cancer: The Manual*, National Institute for Clinical Excellence, London.

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Introduction

This edition refers to occupational therapy in the treatment of conditions such as cancer and others requiring palliative care and also aims to encompass other illnesses than cancer that result in a chronic debilitating condition or non-curable disease and which might be life-threatening. The occupational therapist assesses and analyses functional problems in any illness irrespective of the origin of the disease, but it is the diagnosis and prognosis that affects the intervention and urgency with which the occupational therapy service is needed. Occupational therapists aim to maintain the people whom they are treating at their optimum independence and quality of life. This is carried out preferably in their own homes by controlling symptoms and providing home-care support together with training for the carers. Intervention occurs from the early stages of health promotion to the more advanced stages when disability and illness have become more severe and chronic. A holistic, client-centred approach is needed, which is constantly reassessed according to the needs of the individuals and their carers. The fundamental areas in which occupational therapy contributes include:

- assisting clients with activities for the treatment of physical dysfunction;
- retraining clients in personal and domestic activities that are necessary for daily living;
- assessing seating needs and prescribing wheelchairs and pressure relieving cushions;
- retraining clients in order to help them with cognitive and perceptual dysfunction;
- splinting to prevent deformities and control pain;
- making home assessments;
- referring to and liaising with social services for ongoing home assessment and provision of equipment;
- helping with lifestyle management including investigating hobbies and leisure pursuits;
- providing advice on and education about relaxation techniques;
- aiding breathlessness management;
- aiding management of fatigue and energy conservation;

- providing support and education for carers;
- assisting with psychological adjustment and goal-setting related to loss of function.

In order to establish rapport and introduce the occupational therapy service to clients, the occupational therapist can make them aware of the services that are available, even if those services are not required immediately. If clients know what is available and where to obtain it they can make use of appropriate services at a later date as and when necessary. This avoids needless struggle and avoids the occupational therapy intervention occurring at a time of crisis, when it could be called upon earlier, thus preventing the crisis from happening.

As the assessment of each client covers many aspects of life it is necessary for an occupational therapist to establish a good rapport with the individual. Even the simplest of interactions can raise numerous issues. It may be that all the occupational therapist does is provide a padded bathboard to help an individual wash comfortably. The ramifications of this include:

- giving clients the choice of when to bathe rather than them having to wait for a carer;
- reducing anxiety;
- promoting self-esteem;
- maintaining dignity
- enabling privacy
- avoiding being dependent on others;
- providing safety.

The range of services available to individuals with cancer, or any life-threatening illness, continues to change dramatically and there is now firm emphasis on multiprofessional teamwork rather than on medical and nursing staff alone. Occupational therapy is one part of the service provided by the multiprofessional team and it relies on early referral, ongoing communication and liaison and support for all its members if it is to work efficiently and effectively. In particular, the entire team needs to be aware of the changing needs of the individual as the disease progresses.

The multiprofessional team in oncology and palliative care is likely to comprise:

Occupational therapist
Physiotherapist
Speech and language therapist
Community liaison
Home-care nurse
Social worker
Psychological medicine

Nursing staff
Dietitian
Pastoral care
Surgical appliance officer
Art therapist
Medical staff

The National Council for Hospice and Specialist Palliative Care Services (2000) states that: 'effective rehabilitation is achieved through the work of a well-integrated team of professionals from different disciplines.' Team members must develop an understanding of each other's roles within the team. There will inevitably be some overlap and blurring of roles if team members are working closely together, and if members are sensitive to patients' needs to deal with key individuals. The most important members of the team are the patients, their family and carers.

Occupational therapists find that defining their own role clearly helps them cope with working with the acutely or terminally ill. It should, however, be borne in mind that while clear role identification enables health care workers to achieve their goals, this should not prevent people from working together where boundaries overlap and complement each other.

Providers of oncological and palliative care are increasingly employing occupational therapy services as there is greater emphasis on supporting individuals in their own homes. Occupational therapists have taken the initiative to develop networking and communication within the profession by establishing the Specialist Section of HOPE (Occupational therapists working in HIV/AIDS, Oncology and Palliative Care Education). This, together with growing numbers of palliative care modules in postgraduate education, indicates a rising need for occupational therapists and the expansion of education in these areas.

REFERENCE

National Council for Hospice and Specialist Palliative Care Services (2000) *Fulfilling Lives. Rehabilitation in Palliative Care*, Land and Unwin Ltd, Northamptonshire.

1 What is Cancer?

JILL COOPER

Cancer is a general term applied to tumours or growths. The terms oncology, anaplasia, neoplasms may all be used as an alternative to the word cancer. Body cells normally regenerate and die continually so the number of cells remains constant. Cancer is the disordered and uncontrolled growth of cells within a specific organ or tissue type. If left untreated, they grow steadily resulting in a mass, tumour or growth. The tumour may be benign or malignant. Benign tumours grow slowly and do not recur after excision. They can still be life-threatening if untreated as they can affect vital organs. They are usually curable if they are treated early.

The human body is made up of 10 trillion cells (Knight, 2004), and there are over 100 different types of cells. 25 million cells are replaced every second in adult life. All cells replicate themselves, usually 50–60 times before cell death. Malignant cells grow in an irregular pattern (Gabriel, 2004, p. 4). The smallest detectable tumour is approximately 1 cm in diameter and already contains 1 billion cells. Normal cells know when to grow, to specialize (differentiate), to die (apoptosis), to release certain products or proteins needed by other cells to grow and how to build complex tissue structures.

Cancer is not a single disease but a complex sequence of events (Haylock, 1998). Cancers not only develop at a single site, but also result from malignant change within a single clone, or cluster, of cells. This then multiplies and acquires different changes that give it a survival chance over its neighbours. Cancer cells develop when they have defects in regulation that govern normal cell proliferation and homeostasis, i.e. they lose the ability to die and continue to multiply.

Tobias and Eaton (2001) describe how several steps are required before a normal cell becomes a malignant one. Cell growth and division is profoundly influenced by the presence of critical genes. Oncogenes drive the cell towards malignancy and suppressor genes mutate and result in a loss of normal regulatory or restraining function.

Woodhouse *et al.* (1997) describe the process by which cancer cells spread or metastasize:

- angiogenesis: the generation of blood vessels around the primary tumour that increases the chances for tumour cells to reach the blood stream and colonize in secondary sites;
- attachment or adhesion: tumour cells need to attach themselves to other cells and/or cell matrix proteins;
- invasion: tumour cells move across the normal barriers imposed by the extracellular matrix;
- tumour cell proliferation: new colony of tumour cells is stimulated to grow at a secondary site.

Malignant tumours, therefore, infiltrate and destroy the normal tissues surrounding them and spread to other sites either by blood or the lymphatic system. These are then called metastases or secondaries.

Although terminal and palliative care are phrases often used interchangeably, terminal actually refers to individuals who are actively dying so likely to be in the last few days of life. A diagnosis of cancer does not necessarily mean that the disease will become terminal and the phrase terminal illness can refer equally well to the end stages of neurological, viral or respiratory illness.

Palliation refers to the alleviation of symptoms rather than the attempt to cure disease and it is associated with the advanced stages of all diseases including cancer and HIV/AIDS. The World Health Organization (WHO) (1990) defines palliative care as ‘the active total care of patients and their families by a multiprofessional team when the patient’s disease is no longer responsive to curative treatment.’ In occupational therapy there is not a finite point between acute and palliative care. The focus may change from one to the other as the client progresses or deteriorates. Symptoms are approached in a similar manner and treatment depends on the client’s functional status. Dysfunction may be the result of the tumour and/or side-effects of medical intervention such as chemotherapy, radiotherapy or surgery.

CLASSIFICATION OF TUMOURS

Tumours are classified according to histogenesis – the tissues and cells where they originate. Cancers are often described in terms of degrees of differentiation. The tumour’s degree of differentiation is the extent to which it resembles the normal tissue from which it is derived. If it closely resembles the normal tissue it is well differentiated, otherwise it is poorly differentiated. When tumour cells lose all similarity to the corresponding normal tissue, they are referred to as undifferentiated or anaplastic. Tumours of the muscle and connective tumours are classified as in Table 1.1.

Table 1.1 Nomenclature of connective tissue and muscle tumours

Tissue of origin	Benign tumours	Malignant tumours
Fibrous tissue	Fibroma	Fibrosarcoma
Adipose (fatty) tissue	Lipoma	Liposarcoma
Bone	Osteoma	Osteosarcoma
Cartilage	Chondroma	Chondrosarcoma
Connective tissue near joints	Benign synovioma	Synovial sarcoma
Blood vessel endothelium	Haemangioma	Haemangiosarcoma
Lymph vessel endothelium	Lymphangioma	Lymphangiosarcoma
Smooth muscle	Leiomyoma	Leiomyosarcoma
Striated muscle	Rhabdomyoma	Rhabdomyosarcoma

(From Gowing and Fisher (1989) cited in Cooper (1997))

INCIDENCE

The incidence of cancer is increasing possibly due to lifestyle and the increasing age of the population (Gabriel, 2004, p. 11). There are 1:250 men and 1:300 women diagnosed as suffering from cancer every year (Souhami and Tobias, 2003). As the elderly population grows and as more people with cancer live longer due to better treatment, there are increasing numbers of people with residual dysfunction and disabilities who require occupational therapy. Although the treatment and management of the primary tumour have obviously been the main focus of medical input, metastatic spread is still the main cause of death (Woodhouse *et al.*, 1997). This spread often develops before diagnosis and treatment have begun, so prognosis is not altered by treatment of the primary cancer.

The highest recorded incidences of cancers in females in England in 2002 are breast, lung and colorectal cancers. Those in males are prostate, lung and colorectal cancers (Office for National Statistics, 2005). Early intervention with cancer treatment invariably has a better chance of survival.

AETIOLOGICAL FACTORS

In many types of cancer there is still no clear evidence of what triggers the initial malignant change. Some factors are known: they are listed in Table 1.2.

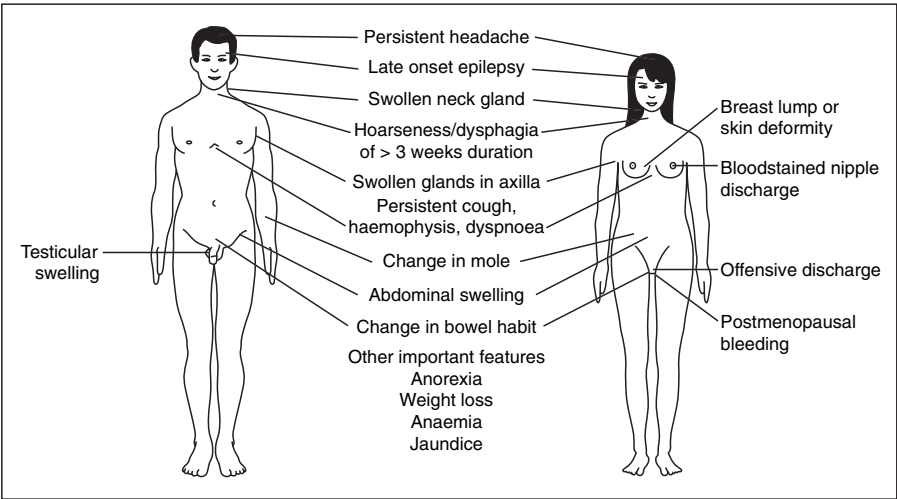
Diet is emerging as an increasingly important risk factor for lower bowel cancers.

Table 1.2 Aetiology of cancer

<i>Ionizing radiation</i>	
Atomic bomb and nuclear accidents	Acute leukaemia and breast cancer
X-rays	Acute leukaemia, squamous cell skin carcinoma
Ultraviolet irradiation	Basal cell carcinoma, squamous cell skin carcinomas, melanoma
Background irradiation	Acute leukaemia
<i>Inhaled or ingested carcinogens</i>	
Atmospheric pollution with polycytic hydrocarbons	Lung cancer
Cigarette smoking	Lung cancer, laryngeal cancer, bladder cancer
Asbestos	Mesothelioma, bronchial carcinoma, lung cancer
Arsenic	Lung cancer, skin cancer
Aluminium	Bladder cancer
Aromatic amines	Bladder cancer
Benzene	Erythroleukaemia
Polyvinyl chloride	Angiosarcoma of the liver

(From Cooper 1997)

SYMPTOMS



(From Tobias and Eaton 2001. Reproduced by kind permission of Bloomsbury Publishing plc)

Figure 1.1 Common symptoms and signs of cancer

INVESTIGATIONS

SCREENING

Breast and cervical cancer screening is well established; breast cancer screening is only certain for females aged over 50 years. Cervical screening programmes are offered as often as resources allow. Trials have failed to show efficacy for lung cancer screening, and testicular cancer has such a good cure rate that screening could only enhance prognosis.

STAGING

Staging identifies the stage that the disease has reached and is one way of establishing the factors that are likely to influence prognosis in any individual. The TNM system evaluates the tumour by size, lymph node spread and presence of distance metastases:

- T – tumour size, site and depth of the primary tumour's invasion depending on the type of tumour, evaluated on a scale ranging from T1–T5;
- N – lymph node spread, evaluated on a scale ranging from N1–N5;
- M – the presence of distance metastases, evaluated on a scale ranging from M1–M5;
e.g. T3, N1, M0 laryngeal cancer implies a primary tumour sufficiently locally advanced to have affixed the vocal cord and early lymph node invasion causing a palpable swelling in the neck but no evidence of metastatic spread.

OTHER INVESTIGATIONS

The individual undergoes many of the following investigations in order for diagnosis and treatment procedures to be established:

- x-ray
- blood counts
- enzymes
- ultrasound
- computed tomography (CT) scan
- positron emission tomography (PET) scan
- magnetic resonance imaging (MRI) scan
- isotope scanning
- surgery.

TREATMENTS/INTERVENTIONS

SURGERY

Cancer surgery is classified as:

- diagnostic and staging – biopsy taken. Primarily curative, where local control of cancer is essential as the primary site either causes or contributes substantially towards death;
- adjuvant – used alongside chemotherapy and/or radiotherapy;
- prophylactic – laser surgery to remove premalignant cells and preventing further tumour growth;
- reconstructive – to rebuild areas removed by other surgery;
- palliative – used in symptom control if a tumour compresses other areas or a nerve block is required for pain control;
- emergency – to remove a life-threatening obstruction;
- surgery for metastases;
- surgery for vascular access – insertion of Hickman line (central intravenous line) in the superior vena cava or right atrium through which chemotherapy can be given. Also insertion of feeding gastrostomy;
- laser surgery.

RADIOTHERAPY

Radiotherapy is the use of ionizing radiation to destroy cancer cells. The aim is to destroy or inactivate cancer cells while preserving the integrity of normal tissues within the treatment field. It is often able to control the tumour with minimal physiological disturbance. There are different types of radiotherapy, and these should be matched to the individual's diagnosis and needs. The factors taken into account when planning radiotherapy include the type and stage of tumour, localization of tumour and adjacent normal structures.

Detailed planning is needed and this may include the preparation of an individually moulded cast. The individual wears this during radiotherapy and it positions him or her correctly. The exact positioning and dosage of radiotherapy is calculated. Radiographers position the individual on the couch, using marks made on the skin in indelible ink, and the radiation beam is switched on. Radiographers or radiotherapists observe the individual via a window or closed-circuit TV in the treatment area, using an intercom for communication.

Radiotherapy is used alone or adjuvant to surgery and/or chemotherapy. In addition to treating localized tumours it is often used as a palliative treatment to relieve pain or bleeding, or to suppress bone metastases which are developing into pathological fractures. Side-effects may include:

- fatigue and malaise, sometimes caused by bone marrow depression;
- anorexia, nausea and vomiting;

- alopecia;
- inflammation around the site being treated, causing internal side-effects such as mucositis, oesophagitis, laryngitis, diarrhoea, cystitis;
- anxiety and altered body image.

CHEMOTHERAPY

Chemotherapy is the use of cytotoxic (cell poisoning) drugs to kill cancer cells. The drugs enter the bloodstream and destroy cancer cells by interfering with the cells' ability to grow and divide. Although normal cells can be damaged, most healthy tissue grows back again.

Chemotherapy can be used in the following ways:

- neo-adjuvant – given prior to surgery to shrink the tumour with the aim of making surgery easier as there is less tumour and increased likelihood of cure;
- adjuvant – in combination with radiotherapy or surgery to eliminate micrometastases and increase the likelihood of cure in some cancers;
- primary or curative – given on its own or in combination with other modalities with the aim of eradicating all tumour cells;
- palliative – aims to improve quality of life though not necessarily increase life expectancy.

Methods of administration:

- oral
- intravenous/intra-arterial
- intramuscular/subcutaneous
- intracavity
- intrathecal
- intralesion
- topical.

Most cytotoxic drugs are toxic to bone marrow so lower the blood cell count. Blood tests are carried out regularly to ensure the individual is strong enough to cope. When very high dose chemotherapy is given, bone marrow is taken from the client before treatment and returned later so the marrow is not affected by the drug.

Short-term side-effects may include:

- hair loss
- nausea and vomiting
- constipation or diarrhoea
- stomatitis, cystitis
- pain at tumour site or jaw