

DIARY

This diary was created as part of the Adelaide Hills Palliative Care Project, and thanks go to all the patients and Health Care Professionals in the Adelaide Hills for their valuable comments and input. Without their participation this resource would never have been possible.

Deb Rawlings
Adelaide Hills Division of General Practice
PO Box 1507
Mount Barker, SA 5251

September 2006

Design, printing and binding by Hyde Park Press, South Australia.

INTRODUCTION

This diary belongs to you, to enable you to keep a record of what is happening. You can write in it yourself, or perhaps ask one of your health care professionals to help you fill it out. This will mean you are an active member of your health team.

It would be a good idea to take this diary with you when you attend an appointment anywhere, or if you are admitted to hospital. It is useful to have all your information from varying doctors, appointments and so on, in the one place. You can let your health care professionals know that you are keeping your own records.

This will mean that all health professionals can have access to what has been happening, what treatment you have received, what medication you are on, tests you have had, and so on. You could also ask any member of the professional team looking after you to write in it, so that they can communicate with each other.

The contents of this diary are personal and confidential.

If found please contact the following:

Name:

Contact Numbers below:

Home:

Work:

Mobile:

INDEX

Section One: **PERSONAL DETAILS**

This is to record your personal details. Things such as your name, address, date of birth. Who your next of kin is. Your medicare and other numbers. What help you have at home. The professionals you are seeing. The sorts of things that health care professionals need to know to help plan your care.

Section Two: **CURRENT MEDICATION**

Keeping track of your medication can often be difficult, especially if you are seeing more than one doctor, each of whom may be prescribing medication (for example you may see your GP as well as your Hospital Specialist). Your GP may be able to provide you with a copy of your medications from the computer.

It also important that everyone knows what other medicines or remedies you are also taking, that may not have been prescribed by a Doctor. This could include vitamins, herbal remedies and naturopathic medicines.

Section Three: **TESTS, APPOINTMENTS & INVESTIGATIONS
BLOOD TESTS**

This is to help keep track of your appointments, such as with your GP, Hospital Specialist, or perhaps for a blood test or investigation. Any health care professional should be able to help you with this if you are not sure

Section Four : **COMMUNICATION SHEET**

This is a communication sheet, which can be useful for yourself and for the people looking after you. It can be used by anyone to communicate with anyone else, to write down notes or messages for each other, and so on....

INDEX (cont.)

Section Five: **USEFUL CONTACT NUMBERS**

This may be a helpful guide to local and state organisations that can help support you and your family, or just for useful contact numbers.

Section Six: **NOTES SECTION**

These notes pages can be used only if you need them, for reminders (as scrap paper) or perhaps for questions to ask your Doctor or Nurse. This section is optional.

Section Seven: **DICTIONARY**

A useful dictionary of all those things you're not really sure what they are or what they mean!

PERSONAL DETAILS

My Name: _____

Preferred Name: _____

Date of Birth: _____

My Address: _____

My Telephone Number: _____

My Mobile Number: _____

My next of kin is:	Second Contact:
Address: <u>Phone Numbers</u> Daytime: Mobile: After Hours:	Address: <u>Phone Numbers</u> Daytime: Mobile: After Hours:

My GP / Family Doctor is:
Surgery Address: <u>Phone Numbers</u> Daytime: After Hours:

PERSONAL DETAILS (cont.)

My Community Nurse is:	My Palliative Care Nurse is:
<u>Phone Numbers</u>	<u>Phone Numbers</u>
Daytime:	Daytime:
After Hours:	After Hours:

Medicare Number:	
Private Health Ins.	<u>Insurer:</u>
	<u>Number:</u>
DVA:	<u>Number:</u>
Pension Card:	<u>Number:</u>
Health Care Card:	<u>Number:</u>
Ambulance:	<u>Number:</u>
Other:	
Other:	

My Hospital Record Numbers are:	
<i>Name of Hospital</i>	<i>Record Number</i>
1.	
2.	
3.	
4.	
5.	

PERSONAL DETAILS (cont.)

Health History

Current Illness:

Past Medical History:

Past Treatments and Operations (type of surgery, date or year):

My Medical Specialists are:

<i>Name</i>	<i>Organisation</i>	<i>Phone Number</i>

PERSONAL DETAILS (cont.)

My Other Health Care Professionals are:		
<i>Name</i>	<i>Organisation</i>	<i>Phone Number</i>

This could include physiotherapists, dieticians and so on, from your local Community Health Service or others you may see in Adelaide.

- See also Medication section for Pharmacist / Alternative Therapists

PERSONAL DETAILS (cont.)

I have the following services in place (eg: meals on wheels, home help)

DATE	SERVICE	CONTACT	OUTCOME

Referrals have been made for the following services:

DATE	SERVICE	CONTACT	OUTCOME

I have completed an Enduring Power of Attorney (MEDICAL)

Contact:

I have completed an Enduring Power of Attorney (FINANCIAL)

Contact:

I have completed a Living Will / End of Life Directive / Good Palliative Care Order (Provide copies of End of Life Directives)

Contact:

CURRENT MEDICATION

ALLERGIES: _____

Name of tablets or medicine	How much how often	Reason for taking	Start Date	Date & Reason for Stopping	Signature
<i>Paracetamol (example)</i>	<i>2 tablets 4 times a day</i>	<i>Pain</i>	<i>12/5/05</i>	<i>14/5/05 – pain controlled</i>	

PHARMACY/ CHEMIST ATTENDED: _____

CURRENT MEDICATION

ALLERGIES: _____

Name of tablets or medicine	How much how often	Reason for taking	Start Date	Date & Reason for Stopping	Signature
<i>Paracetamol (example)</i>	<i>2 tablets 4 times a day</i>	<i>Pain</i>	<i>12/5/05</i>	<i>14/5/05 – pain controlled</i>	

PHARMACY/ CHEMIST ATTENDED: _____

DICTIONARY



Acquired immune deficiency syndrome (AIDS): A viral disease that destroys the body's ability to fight infections, leaving the body susceptible to many other diseases.

Acute: A sudden onset of symptoms or disease.

Adenocarcinoma: See Carcinoma.

Adenoma: A benign tumour made up of glandular tissue. For example, an adenoma of the pituitary gland may cause it to produce abnormal amounts of hormones.

Adrenal Glands: Two small organs near the kidneys that release hormones.

Advance Directives: An advance directive enables you to record your wishes about medical care and treatment in advance. Should you then no longer be medically competent, and unable to make your own decisions your wishes will have been recorded.

AFP (Alpha fetoprotein): A tumour marker.

Alopecia: The loss of hair, which may include all body hair as well as scalp hair.

Analgesic: Any drug that relieves pain. Aspirin and Paracetamol are mild analgesics.

Anaemia: A condition in which a decreased number of red blood cells may cause symptoms including tiredness, shortness of breath, and weakness.

Anorexia: The loss of appetite.

Antibody: A substance formed by the body to help defend it against infection.

Antiemetic agent: A drug that prevents or controls nausea and vomiting.

Antifungal agent: A drug used to treat fungal infections.

Antigen: Any substance that causes the body to produce natural antibodies.

Antineoplastic agent: A drug that prevents, kills, or blocks the growth and spread of cancer cells.

Arrhythmia: An irregular heartbeat.

Aspiration: The process of removing fluid or tissue, or both, from a specific area.

Autoimmunity: A condition in which the body's immune system mistakenly fights and rejects the body's own tissues.

Axilla: The armpit.

Axillary nodes: Lymph nodes – also called lymph glands – found in the armpit (axilla).



Barium enema: The use of a milky solution (barium sulfate) given by an emema to allow x-ray examination of the lower intestinal tract.

Barium swallow: The use of a milky solution (barium sulfate) given orally to allow x-ray examination of the upper intestinal tract.

Benign growth: A swelling or growth that is not cancerous and does not spread from one part of the body to another.

Biopsy: The surgical removal of tissue for microscopic examination to aid in diagnosis.

Blood cells: Minute structures produced in the bone marrow; they consist of red blood cells, white blood cells, and platelets.

Blood count: The number of red blood cells, white blood cells, and platelets in a sample of blood.

Bone marrow: The spongy material found inside the bones. Most blood cells are made in the bone marrow.

Bone marrow biopsy and aspiration: The procedure by which a needle is inserted into a bone to withdraw a sample of bone marrow.

Bone marrow suppression: A decrease in the production of blood cells.

Bone marrow transplant: The infusion of bone marrow into a patient who has been treated with high dose chemotherapy or radiation therapy. Patients may use their own marrow, which in some cases has been frozen.

Allogeneic: The infusion of bone marrow from one individual (donor) to another.

Autologous: The infusion of a patient's own bone marrow previously removed and stored.

Syngeneic: The infusion of bone marrow from one identical twin into another.

Bone Scan: A picture of the bones using a radioactive dye that shows any injury, disease, or healing. This is a valuable test to determine if cancer has spread to the bone, if anticancer therapy has been successful, and if affected bony areas are healing.

Breast self-examination (BSE): A manual self-examination of the breasts.

Bronchoscopy: The insertion of a flexible, lighted tube through the mouth into the lungs to examine the lungs and airways.



Cancer: A group of diseases in which malignant cells grow out of control and spread to other parts of the body.

Cancer in situ: The stage where the cancer is still confined to the tissue in which it started.

Candida: A common fungal infection.

Carcinogen: A substance that causes cancer. For example, nicotine in cigarettes is a carcinogen that causes lung cancer.

Carcinoma: A type of cancer that starts in the skin or the lining of organs.

Adenocarcinoma: A malignant tumour arising from glandular tissue.

Basal cell carcinoma: The most common type of skin cancer.

Bronchogenic carcinoma: A cancer originating in the lungs or airways.

Cervical carcinoma: A cancer of the cervix (the neck of the uterus).

Endometrial carcinoma: A cancer of the lining of the uterus.

Squamous cell carcinoma: Cancer arising from the skin or the surface of other structures, such as the mouth, cervix, or lungs.

Cardiomegaly: An enlargement of the heart.

Carer: A carer is someone who provides regular care and assistance to another individual who is living at home and is unable to perform tasks of daily living. Carers can be family members (including children), friends and or neighbours.

CAT scan (CT scan): A test using computers and x-rays to create images of various parts of the body.

CEA (Carcinoembryonic antigen): A blood tumour marker.

Cellulitis: The inflammation of an area of the skin (epithelia layer).

Central venous catheter: A special intravenous tubing that is surgically inserted into a large vein near the heart and exits from the chest or abdomen. The catheter allows medications, fluids, or blood products to be given and blood samples to be taken. (Examples of types of central venous catheters are Broviac, Groshong, Hickman, etc.).

Cervical nodes: Lymph nodes in the neck.

Chemotherapy: The treatment of cancer with drugs.

Combination chemotherapy: The use of more than one drug during cancer treatment.

Chronic: Persisting over a long period of time.

Colonoscopy: A procedure to look at the colon or large bowel through a lighted, flexible tube.

Colostomy: A surgical procedure by which an opening is created between the colon and the outside of the abdomen to allow stool to be emptied into a collection bag.

Congestive heart failure: A build-up of fluid in the lungs or extremities, or both (especially the legs). This occurs if the heart cannot pump the blood adequately.

Cyst: An accumulation of fluid or semisolid material within a sac.

Cystitis: An inflammation of the bladder.



Drug resistance: The result of cells' ability to resist the effects of a specific drug.

Dysphagia: Difficulty in swallowing.

Dyspnoea: Difficult or painful breathing; shortness of breath.

Dysuria: Difficult or painful urination.



Effusion: A collection of fluid in a body cavity, usually between two adjoining tissues. For example, a pleural effusion is the collection of fluid between two layers of the pleura (the lung's covering).

Electrocardiogram (ECG): A test that takes recordings of the electrical activity of the heart.

End of Life Directives: *See advanced directives*

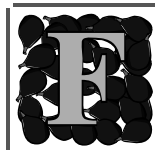
Endoscopy: A procedure looking at the inside of body cavities, such as the oesophagus (food pipe) or stomach.

Enduring Power of Attorney (Medical): Sometimes, due to illness or very old age, people lose the capacity to make medical decisions for themselves. A medical power of attorney means people appoint another person to make medical decisions on their behalf for the times when they are unable to do so themselves.

Erythema: Redness of the skin.

Erythrocyte: The red blood cell that carries oxygen to body cells and carbon dioxide away from body cells.

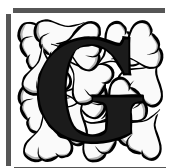
Excision: Surgical removal.



Fine-needle aspirate: A procedure in which a needle is inserted, under local anaesthesia, to obtain a sample for the evaluation of suspicious tissue.

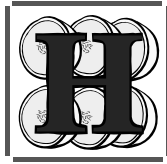
Fistula: An abnormal opening between two areas of the body.

Frozen section: A technique in which tissue is removed and then quick-frozen and examined under a microscope by a pathologist.



Good Palliative Care Plan: Although not a legal document, it is a record of a discussion between the patient, family and the doctor about palliative care or active treatment. The Good Palliative Care Plan is written by a doctor in consultation with legally appointed agents and/or family members.

Granulocyte: A type of white blood cell that kills bacteria.



Hematocrit (Hct): The percentage of red blood cells in the blood. A low hematocrit measurement indicates anaemia.

Haematologist: A doctor who specialises in the problems of blood and bone marrow.

Haematology: The science that studies the blood.

Haematuria: Blood in the urine.

Haemoccult (Guaiac) test: A test that checks for hidden blood in the stool.

Herpes simplex: The most common virus that causes sores often seen around the mouth, commonly called cold sores.

Herpes Zoster: A virus that settles around certain nerves causing blisters, swelling, and pain. This condition is also called shingles.

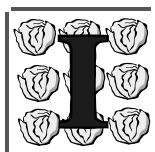
Hickman catheter: A special intravenous tubing that is surgically inserted into a large vein near the heart. See central venous catheter.

Hodgkin's disease: A cancer that affects the lymph nodes. See Lymphoma.

Hormones: Substances secreted by various organs of the body that regulate growth, metabolism, and reproduction.

Hospice: A concept of supportive care to meet the special needs of patients and family during the terminal stage of illness. The care may be delivered in the home or hospital by a specially trained team of professionals.

Human immunodeficiency virus (HIV): The virus that causes AIDS.



Ileostomy: A surgical opening in the abdomen connected to the small intestine to allow stool to be emptied into a collection bag.

Immunity (Immune system): The body's ability to fight infection and disease.

Immunosuppression: Weakening of the immune system that causes a lowered ability to fight infection and disease.

Immunotherapy: The artificial stimulation of the body's immune system to treat or fight disease.

Infusion: Delivering fluids or medications into the bloodstream over a period of time.

Infusion pump: A device that delivers measured amounts of fluids or medications into the bloodstream over a period of time.

Injection: Pushing a medication into the body with the use of a syringe and needle.

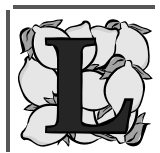
Intramuscular (IM): Injection into the muscle.

Intravenous (IV): Injection into the vein.

Subcutaneous Injection: Into the fatty tissue under the skin.

Interferon: A naturally produced chemical released by the body in response to viral infections. Interferon can be artificially produced and used as a form of immunotherapy.

Interleukin: A naturally produced chemical released by the body.



Laryngectomy: The surgical removal of the larynx.

Lesion: A lump or abscess that may be caused by injury or disease, such as cancer.

Leukaemia: Cancer of the blood. of the blood. White blood cells may be produced in excessive amounts and are unable to work properly.

Leucocyte: See White blood cell.

Leucopenia: A low number of white blood cells.

Living Will: See Advanced Directives

Lumpectomy: See Mastectomy-Segmental.

Lymphangiogram: A test to look at the lymph nodes.

Lymphatic system: A network that includes lymph nodes, lymph, and lymph vessels that serves as a filtering system for the blood.

Lymphoedema: Swelling either from obstructed cancerous lymph nodes or from surgically removed lymph nodes.

Lymph nodes: Hundreds of small oval bodies that contain lymph. Lymph nodes act as our first line of defence against infections and cancer.

Lymphocytes: White blood cells that kill viruses and defend against the invasion of foreign material.

Lymphoma: A cancer of the lymphatic system. Doctors differentiate the different lymphomas by the type of cell that is involved in the makeup of the tumour. Treatments depend on the type of cell that is seen.



Malignant tumour: A tumour made up of cancer cells of the type that can spread to other parts of the body.

Mammogram (Mammography): A low-dose x-ray / picture of the breasts to determine whether abnormal growths or cysts are present.

Mastectomy – Segmental (lumpectomy): Removal of the lump and a small amount of surrounding breast tissue.

Mastectomy – Simple (modified mastectomy): Removal of the entire breast.

Mastectomy – Radical: Removal of the entire breast along with underlying muscle and lymph nodes of the armpit.

Melanoma: A cancer of the pigment-forming cells of the skin or the retina of the eye.

Metastasis: To spread from the first cancer site, for example, breast cancer that spreads to the bone.

Monoclonal antibodies: Artificially manufactured antibodies specifically designed to find targets on cancer cells for diagnostic or treatment purposes.

MRI (Magnetic resonance imaging): A sophisticated test that provides in-depth images of organs and structures in the body.

Mucosa (Mucous membranes): The lining of the mouth and gastrointestinal tract.

Mucositis: Inflammation of the lining of the mouth or gastrointestinal tract.

Myelogram: An x-ray procedure by which a dye is injected into the spinal column to show any pathology of the spinal cord.

Myeloma: A malignant tumour of the bone marrow associated with the production of abnormal proteins.

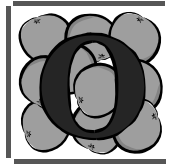
Myelosuppression: A decrease in the production of red blood cells, platelets, and some white blood cells by the bone marrow.



Neoplasm: A new growth of tissue or cells; a tumour that is generally malignant.

Neutropenia: A decreased number of neutrophils, a type of white blood cell.

Non-Hodgkin's lymphoma: A cancer of the lymphatic system. Non-Hodgkin's lymphoma is related to Hodgkin's disease but is made up of different cell types. See Lymphoma.



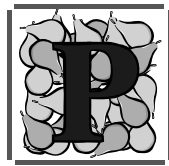
Oedema: The accumulation of fluid in part of the body.

Oesophagitis: Inflammation of the oesophagus (food pipe).

Oestrogen: A female hormone produced primarily by the ovaries.

Oncologist: A doctor who specialises in oncology.

Oncology: The study and treatment of cancer. Doctors who specialise in oncology are called oncologists.



Palliative treatment: Treatment aimed at the relief of pain and symptoms of disease but not intended to cure the disease.

Pap (Papanicolaou) Smear: A test to detect cancer of the cervix.

Paracentesis: Removing fluid from the abdomen using local anaesthesia and needle and syringe.

Pathological fracture: A break in a bone usually caused by cancer or some disease condition.

Pathology: The study of disease by the examination of tissues and body fluids under the microscope. A doctor who specialises in pathology is called a pathologist.

Petechiae: Tiny areas of bleeding under the skin, usually caused by a low platelet count.

Phlebitis: A painful inflammation of the veins.

Photosensitivity: Extreme sensitivity to the sun, leaving the patient prone to sunburns. This can be a side effect of some cancer drugs and radiation.

Placebo: A inert substance often used in clinical trials for comparison.

Platelet (Plt): Cells in the blood that are responsible for clotting.

Platelet count: The number of platelets in a blood sample.

Polyp: A growth of tissue protruding into a body cavity, such as a nasal or rectal polyp. Polyps may be benign or malignant.

Port – Implanted: A catheter connected to a quarter-sized disc that is surgically placed just below the skin in the chest or abdomen. The tube is inserted into a large vein or artery directly into the bloodstream. Fluids, drugs, or blood products can be infused, and blood can be drawn through a needle that is stuck into the disc. Examples: Port-o-cath, Infusaport.

Primary tumour: The original cancer site. For example, breast cancer that has spread to the bone is still called breast cancer.

Progesterone: One of the female hormones produced by the ovaries.

Prognosis: The projected outcome of a disease; the life expectancy.

PSA (Prostate-specific antigen): A marker used to determine prostate disease; it may be A marker used to determine prostate disease; it may be benign or malignant.

Prosthesis: Artificial replacement of a missing body part.

Protocol: A treatment plan.



Radiation Therapy: X-ray treatment that damages or kills cancer cells.

Radiologist: A doctor who specialises in the use of x-rays to diagnose and treat disease.

Recurrence: The reappearance of a disease after a period of remission.

Red blood cells (Erythrocytes): Cells in the blood that deliver oxygen to tissues and take carbon dioxide from them.

Red blood count (RBC): The number of red blood cells seen in a blood sample.

Regression: The shrinkage of cancer growth.

Relapse: The reappearance of a disease after its apparent cessation.

Remission: Complete or partial disappearance of the signs and symptoms of disease.

Respite: Respite is a break for Carers. Respite is about temporarily relieving Carers of their usual caring role by providing suitably trained respite support workers.

Risk factor: Anything that increases a person's chances of developing cancer, for example, smoking and lung cancer.



Sarcoma: A malignant tumour of muscles or connective tissue such as bone and cartilage.

Chondrosarcoma: A malignant tumour of cartilage that usually occurs near the ends of the long bones.

Ewing's sarcoma: A malignant tumour starting in bone, affecting the bones of extremities. It often appears before the age of 20.

Shingles: See Herpes zoster.

Side effects: Secondary effects of drugs used for disease treatment.

Sigmoidoscopy: The visual examination of the rectum and lower colon using a tubular instrument called a sigmoidoscope.

Sputum: Secretions produced by the lungs.

Staging: Determination of extent of the cancer in the body.

Steroids: A type of hormone.

Stoma: An artificial opening between two cavities or between a cavity and the surface of the body.

Stomatitis: Temporary inflammation and soreness of the mouth.

Systemic disease: A disease that affects the entire body instead of a specific organ.



Taste alteration: A temporary change in taste perception.

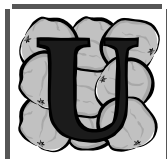
Testicular self-examination (TSE): a simple manual self-examination of the testes.

Thoracentesis (Pleural tap): A procedure to remove fluids from the area between the two layers (pleura) covering the lung.

Thrombocytopenia: An abnormally low number of platelets (thrombocytes). If the platelet count is too low, bleeding could occur.

Tracheostomy: A surgical opening through the trachea in the neck to provide an artificial airway.

Tumour: An abnormal overgrowth of cells. Tumours can be either benign or malignant.



Ultrasound examination: The use of high frequency sound waves to aid in diagnosis.



Venepuncture: Puncturing a vein in order to obtain blood samples, to start an intravenous drip, or to give medication.

Vesicant: A medication or agent that may cause blistering.

Virus: A tiny infectious agent that is smaller than bacteria. The common cold is caused by a virus, and the herpes simplex virus causes cold sores.



White blood cells (WBC): General term for a variety of cells responsible for fighting invading germs, infection, and allergy-causing agents. Specific white blood cells include granulocytes and lymphocytes.

White blood count (WBC): The actual number of white blood cells seen in a blood sample.



X-ray: High-energy electromagnetic radiation used to diagnose and treat disease. Diagnostic test using high energy to visualize internal body organs. See Radiation therapy.