You are invited to a free presentation:

- Dr Mathilda Wilding (Medical Oncology)  
  “Understanding genetic risk for cancer”

- Jessica Medd (Clinical Psychologist)  
  “Caring for the carer”

**When:** Monday, 12th October from 5.00–6.00pm  
**Where:** Medical Education Centre – Lecture Theatre 1, Concord Hospital (entrance off Hospital Rd through Gate 3)

For registration please e-mail: survivorship@sswahs.nsw.gov.au
UNDERSTANDING GENETIC RISK FOR CANCER

Dr Mathilda Wilding
Cancer Genetics Advanced Trainee
Royal Prince Alfred Hospital & Prince of Wales Hospital
OUTLINE

- What causes cancer?
- Inheritance: what are genes?
- Inherited cancer syndromes
  - Breast & ovarian cancer
  - Colon cancer
- Role of the Familial cancer clinic
- Genetic testing
- Insurance
WHAT CAUSES A FAMILY HISTORY OF CANCER?

1. Just by chance, cancer is very common
2. Because family members have environmental and lifestyle influences in common (e.g., smoking cigarettes or sun exposure)
3. An inherited faulty ‘cancer protection’ gene running in the family (5% of cancers)
WHAT CAUSES CANCER?

- Our bodies are made up of billions of tiny cells
- Cancer occurs when cells in the body become abnormal and grow out of control
WHAT ARE GENES?

- Genes are made up of a DNA code.
- Genes provide the recipe (instructions) for our body to function.
- We have approximately 20,000 genes.
- We have two copies of each gene.
- We inherit half of our genes from our mother and half from our father.
WHAT ARE GENES?

- Each gene provides the recipe for a specific protein required by the body.
- Our genes decide features such as the colour of our eyes, hair, skin and height.
- Some genes control cell growth and maintain orderly cell growth and division.
Gene fault (mutation)

- Just like in a recipe for a cake, you need the right ingredients and they need to be added in the right order.

- If the recipe does not work properly or is faulty, the protein may not be produced in the right amount or it may not function properly.

- In some cases this can cause a genetic condition.
**GENE FAULT (MUTATION)**

- Everyone has some gene faults
  - faults can be **acquired** during our life as we age or
  - they can be **inherited** from our parents

- Usually gene faults don't cause any problems

- Occasionally gene faults can make you more prone to particular health problems.
Cancer Protection Genes

- ‘Cancer protection’ genes are the recipes in our cells that control cell growth.
- If these genes are faulty, cells can grow out of control and can form a cancer.
- Faults can occur in ‘cancer protection’ genes during your life due to:
  - environmental factors: smoking, radiation, infectious agents (HPV, hepatitis)
  - the process of ageing
- A small number of people inherit a fault in one of the ‘cancer protection’ genes from a parent.
CANCER PROTECTION GENES

- In order for a normal cell to become cancerous many faults (mutations) need to occur in a number of different ‘cancer protection’ genes.
Cancer Development

This person was born with a faulty cancer protection gene. Variations to cancer protection genes that make them faulty (mutations) caused by ageing and other unknown environmental factors lead to cell growth out of control, which can result in two outcomes: no cancer but more susceptible to becoming cancerous, or no cancer but more susceptible to becoming cancerous. Normal cell growth and no cancer are also noted.
HEREDITARY (INHERITED) CANCER SYNDROMES

- Disorders that may predispose individuals to developing certain cancers
- Caused by an inherited gene fault in a ‘cancer protection’ gene
BREAST & OVARIAN CANCER

BRCA1 or BRCA2 mutation
- 3 or more relatives diagnosed with breast cancer (on the same side of the family)
- Breast and ovarian cancer
- Breast cancer diagnosed under 40 years
- Certain types of ovarian cancer diagnosed <70 years
- Breast cancer diagnosed in a male
- Bilateral breast cancer: two breast cancers
- One woman with breast and ovarian cancer
CASE 1: MODERATE RISK

- Low likelihood of a hereditary cancer syndrome, such as a BRCA1 or BRCA2 mutation
Case 2: Strong family history of breast & ovarian cancer

Recommend genetic testing for a BRCA1 or BRCA2 mutation
BOWEL & UTERINE CANCER

Lynch Syndrome

- 3 or more blood relatives diagnosed with bowel cancer on the same side of the family
- One family member diagnosed with bowel or uterine cancer <50 years
- Family history of Lynch Syndrome related cancers
  - Bowel, uterine (endometrial), ovarian, stomach, small bowel, kidney and bladder
- Tumour pathology
  - Mismatch repair (MMR) immunohistochemistry
CASE 3: STRONG FAMILY HISTORY COLON & UTERINE CANCER
SHOULD I BE REFERRED TO A FAMILY CANCER CLINIC?

- Cancer diagnosed at an early age
- Multiple affected family members
  - Blood relatives on the same side of the family
  - Multiple generations
- Multiple primary cancers in one person
- The pattern of cancer in the family
  - Breast & ovarian cancer
  - Bowel and endometrial (uterus) cancer
- Other clues: Pathology
  - Triple negative breast cancer < 40yrs
  - Ovarian cancer < 70yrs
  - Colon cancer immunohistochemistry
  - Multiple polyps
- Rare cancers
- Mutation identified in family member
ROLE OF THE FAMILIAL CANCER CLINIC

Identifying families at risk:
- Take a thorough family history
- Collect information about cancer type and age at diagnosis for all family members
- Ethnicity may also be important e.g. Ashkenazi Jewish ancestry
WHAT IS GENETIC TESTING?

The first step in a family is to:

- Test an individual's DNA
  - Performed on a blood sample
- Looking for a gene fault, called a mutation
- Almost always performed on a person affected by cancer
- Results of genetic testing take 4-6 weeks
**Predictive Testing**

The second step:
- If a gene fault is identified in an individual, genetic testing is then offered to their family members.
INHERITANCE OF GENE FAULTS

- Autosomal dominant inheritance: the effect of the faulty gene is dominant over the working gene
- 1 in 2 chance (or 50% chance) of inheriting the fault from an affected parent
GENETIC TESTING & INSURANCE

- Private health insurance is **not** impacted by genetic testing.
- Life insurance products may be impacted by genetic testing:
  - Such as life, disability and trauma insurance.
  - May exclude certain conditions, charge higher premium or deny insurance.
- If you **already** have an insurance policy you are not obliged to inform them of genetic testing, unless you alter your policy.
- If you already have been diagnosed with cancer, genetic testing will not change ability to obtain insurance.
**Benefits of Genetic Counseling**

- Can help to clarify the risk of developing cancer
  - Risk assessment tools
  - Arrange tumour testing

- Identify relatives at increased risk of cancer
  - 1 in 2 chance of inheriting same mutation
  - Therefore, 1 in 2 will not carry the gene fault and will be at population risk for cancer

- Recommend risk management options
  - Increased screening: breast screening, colonoscopy
  - Surgical management e.g. removal of ovaries
  - Improved survival

- Treatment options
CONSEQUENCES OF GENETIC TESTING

- Knowledge of increased cancer risk
  - Burden
  - Potential guilt
If you are concerned about your family history

- Talk to your doctor about the:
  - types of cancers that have occurred in your blood relatives
  - The age each person was when they developed cancer

- Your doctor can advise you whether a referral to a Familial Cancer Clinic is needed.
THANK YOU

- Any questions?
RESOURCES

- Centre for Genetics Education
  www.genetics.edu.au

- Familial risk assessment FRA-BOC
  www.canceraustralia.gov.au

- Cancer council
  www.cancercouncil.com.au

Referral to Familial Cancer Centre

- RPA Cancer Genetics
  - Ph 9515 8780 or Fax 9515 5278
CARING FOR CARERS – THEIR CANCER YOUR JOURNEY

Jessica Medd
Clinical Psychologist
Department of Urology
Concord Repatriation General Hospital
RIPPLE EFFECT
WHO IS A CARER?

If you do any of these for family or friends...

Cooking  Medication management
Paying bills  Cleaning
Shopping  Visits to doctors
Transport  Gardening

...you are a carer!
How many carers are there?

According to Carers Australia, there are more than 2.5 million unpaid family carers in Australia. More than 770,000 of these people are primary carers, meaning they provide the most care for the person they are looking after. The average carer spends about 40 hours per week providing care. Women are slightly more likely to be carers than men.

2.5 million unpaid family carers

Approximately 30% are primary carers

Who is a carer?
EMOTIONS

"I get jealous, I get mad, I get worried, I get curious...... It's only because I still care"

Liana Coakley <3
15 Apr 2013 5:30 pm
FEAR

- Learn more about the cancer, generally helps, though for some this increases feelings of being overwhelmed.
- Check in with each other on what you think you need/want to know.
- Using practical strategies to help with medication. Getting pharmacy to help, using online reminders etc.
Anger

- Stop – Breathe – Re think.
- Let the anger out.
- Recognise your triggers.
- Talking to someone may help.
- Notice your warning signals.
- Try to direct anger positively.
- Relaxation/ or meditation.

Love is caring for each other even when you’re angry.

Lessons Learned In Life
LONELINESS

- Keep in contact with family, even if they don’t keep in contact with you!
- Make contact with someone on a daily basis.
- Ask a friend to ring you every few days.
- Accept help! (Say YES!)
- Arrange for visitors.
STRESS

- Recognise the signs.
- Exercise regularly.
- Meditate or practice slow breathing.
- Do something you find relaxing – music, reading.
- Talk to someone.
- Ask others for help – YES ASK!
- Try to rest and get sufficient sleep.
- Eat well or ask GP about supplements.
- Take time out for yourself – respite care can be used to give you a break.
DEPRESSION
Symptoms
- Feeling sad/empty
- Losing interest and pleasure
- Change to appetite
- Change to sleep pattern
- Fatigue
- Concentration
- Memory
- Sense of worthlessness/helplessness

Activity scheduling.
- Structure your day.
- Schedule coffee/chats with friends.
- Exercise each day.
- Writing a diary
- Acknowledging feelings
- You are only human!

Depression is not a sign of weakness
it means you have been strong for far too long
NOT NEEDED ALWAYS
RELATES TO DYING.

LOSS OF RELATIONSHIP AS IT WAS, CHANGE IN ROLES, INTIMACY.

LOSS OF YOUR PREVIOUS ROLE – WORK, SOCIALLY AND SO ON.

FINANCIAL CHANGES.

I SAW YOUR GRIEF AND LOSS. THERE WAS NOTHING I COULD DO BUT FEEL A TINY BIT OF IT WITH YOU.
GUILT

Talk about how you are feeling

Try to avoid words like “should” and “must”.

a feeling of responsibility or remorse for some offense, crime, wrong, etc., whether real or imagined.
SELF CARE

"IF YOU DON'T TAKE CARE OF YOUR BODY, WHERE ARE YOU GOING TO LIVE?"

~UNKNOWN
WAYS TO COPE

- Keep a diary of your thoughts and feelings.
- Keep your expectations in check – nobody is perfect!
- Try to take time out for yourself – ASK FOR HELP – put your hand up.

- Care for your body – food, rest, exercise.
- Organise your time and use a calendar.
- Respite care.
- Did I mention to ask for help??!
CHECKING IN WITH YOUR VALUES
INTIMACY

You can still make music ... to the beat of a different drum.
GET PROFESSIONAL HELP
**CONCLUDING COMMENTS**

- Caring involves a change in roles.
- Caring has challenging times (as well as rewarding ones).
- Caring invokes a range of emotions, some not so welcome.
- Trying to understand the reason behind these emotions is a start to trying to manage them.
- Did I mention about asking for help? – from friends and family as well as professional help.
RESOURCES AND FURTHER INFORMATION

- Caring for Someone with Cancer – Cancer Council.
- The beyondblue Guide for Carers – Supporting and caring for a person with depression, anxiety and/or a related disorder.
- beyondblue.com.au – heaps of information and fact sheets on male depression and how to help.
- Find your local support group – at Concord we have support groups for bowel and prostate and breast cancer.
Nobody cares how much you know, until they know how much you care. ~ Theodore Roosevelt
It’s such an individual thing. Be kind to yourself and just have the knowledge that there is no right or wrong way to do it.
Young Carers Needs

Family and relationships
Closeness, conflict, tension, respect, commitment

Health and wellbeing
Physical, emotional, mental health

Transition to adulthood
When can I leave home?

Identity
How they see themselves: proud; different; not that special...

Employment
Choice of profession, balancing

Financially
Low income, marginalised, cost of treatment and medications

Social life
Going out, having friends over, involvement in sport, music, hobbies

Skills development
Cooking, finances, budgeting, advocacy, communication, negotiation, flexibility

Education
Attendance, concentration, performance, bullying, homework, lateness, high achieving

Source: Carers Victoria