# **ENHANCING MELANOMA SURVIVORSHIP**

# YOUR PERSONAL MELANOMA DIARY

FOR USE BY YOU, YOUR GP AND YOUR SPECIALISTS













# YOUR PERSONAL DETAILS

Adding your personal details to this page may save you time and effort as you will have commonly requested information at hand.

Name							
Address							
	(M)						
	Contact number						
Veterans Affairs number							
	ne N						
•		•					
List any other significant m	ANOMA RELATE edical conditions you have t failure, recent operations)	had in the past or are curre	ently being treated for				
Date	Condition						
	1						
List here any prescribed m	nedication or anything else	you take regularly.					

# OTHER CONTACT DETAILS

There may be many people and institutions involved in your care e.g. your regular GP, a GP you visit for melanoma surveillance and several different specialists e.g. a dermatologist, a dietician or an occupational therapist. List them here to help them work together better.

ROLE	NAME	CONTACT INFORMATION
Example Regular General Practitioner	Dr Jane Doe	123 Mt Alexander Street West Springvale 9765 1234

# YOUR MELANOMA DETAILS

## **Thickness and Stage**

The most important facts regarding your melanoma are the "thickness" of the primary tumour and the stage of your disease. Your doctor can assist you obtain and use this information. Your pathology report will record the "thickness" and "level" of the tumour but do not confuse the "level" of the tumour reported there with the "disease stage". Your doctor can check the disease stage at the following address

http://www.cancerstaging.org/staging/posters/melanoma8.5x11.pdf

Date of Diagnosis	Body Location	Breslow thickness	Disease Stage

## **Prognosis**

Describe what you have been told about the risk melanoma represents to your health and survival (i.e. your overall prognosis).

Date	Future Risk

### Risk of a second or multiple melanoma

To learn about your risk of getting a further primary melanoma, fill in the table below with help from your doctor, then visit http://victorianmelanomaservice.org/calculator/index.php

Number of common nevi on the arm	None	1 to 5	6 to 10	10+		
Number of atypical nevi	None	1	2	3	4	5+
Freckling	None	Few	Moderate	Many		

The overall risk of developing a second melanoma is about 0.5% per year (or 4.5% risk over 10 years). The risk for a further melanoma increases progressively with increasing numbers of new melanomas. For example, if you have had 2 melanomas the risk for a third is about 3% per year.

Incidence of a second melanoma also peaks around the ages of 25-34, which may reflect their occurrence in individuals from melanoma prone families who tend to develop multiple melanomas earlier in life.

Those diagnosed with their first melanoma before age 45 have about twice the risk of developing a second compared to the older group though the risk of a second melanoma is higher in males over 70.

# **SURVEILLANCE AND TREATMENT PLAN**

As you complete the initial diagnosis and treatment phase of your melanoma disease it is essential to understand how to successfully continue to manage your disease.

Surveillance Process	wno	Frequency
Self skin examination		
Total skin examination		
Lymph node palpation		
Total body photography		
Specific lesion sequential dermoscopy		
Ultrasound Not routinely required		
PET scan  Not routinely required		
CT scan  Not routinely required		
Other (specify)		
Treatment Interventions		
Surgery	Not Required Treatment completed	Treatment planned
Radiotherapy	Not Required Treatment completed	Treatment planned
Medical therapies	Not Required Treatment completed	Treatment planned
Good Health Measures	Sun Protection/Exercise/Activities/E	Diet/Alcohol/Smoking
Other (specify		

# **MELANOMA EVENTS RECORD AND PLAN**

This register is designed to provide you, and those that help you, see exactly what has happened to you to date, to trace any information that may be needed and to clearly set out the next step.

The examples are to guide you as to what you should enter. Make a record each time you have an appointment for a consultation or test. Try and compile a record of everything that has happened to date.

Date	What event and where?	Result	Next Step	
1/12/2011	Skin biopsy at GP - Dr Brown's	Melanoma diagnosed	Referred to Victorian Melanoma Service at The Alfred	
6/12/2011	Saw Mr Smith - dermatologist at Alfred	Recommended surgery	Referred to Mr Jones plastic surgeon at his Malvern rooms	
9/12/2011	Saw Mr Jones - plastic surgeon in his rooms	Confirmed need for surgery	Surgery scheduled for 15/12/2011	

Date	What event and where?	Result	Next Step

# **MELANOMA EVENTS RECORD AND PLAN**

Date	What event and where?	Result	Next Step
	<u>l</u>	L	

# **INVESTIGATION SUMMARY AND REPORTS**

This page is to assist any medical practitioner who is caring for you locate any past investigation that may be relevant to them. You can choose to ask doctors for a copy of the actual report and store it here in your diary or you can ask them to write down a reference number for the laboratory or institution record where that report will be held. This page will duplicate the events record to some extent but will be very useful.

Date	Investigation/Test	Reference number or Record location

# **SELF SKIN EXAMINATION**

#### **FREQUENCY**

See your surveillance plan on page 5.

#### TRUST YOUR EYES and YOUR INTUITION

- Self skin examination is very useful as it is known that up to 70% of melanomas on the skin are
  first detected by someone who has had no specific training or knowledge about melanoma and
  sometimes this happens even before it looks like a melanoma to a doctor.
- You can do it!!!

#### LOOK FOR ANYTHING THAT IS NEW OR CHANGING

- · You cannot easily learn to recognise melanoma.
- However, the ABCDE rule (below) may help you know what is frequently found.
- Photography can assist by allowing a true comparison over time.
- If something is unchanged over 3 to 6 months it is unlikely to be melanoma. If something is new or changing then it needs assessment to determine if biopsy is required.

#### YOU MAY SEE

- A: Asymmetrical shape
- B: Border irregularity
- C: Colour variation and change
- D: Diameter (size) >6mm
- E: Evolving i.e. changing or growing
- F: A lump in or under the skin

#### YOU MAY FEEL

- · Pain, numbness or tingling
- · Bleeding, ulceration, or weeping
- · Inflammation or redness

#### DON'T FEEL RESPONSIBLE: DON'T BE SHY

- Your role is only to discover potential problems to show your doctor.
- Never feel embarrassed or inhibited to ask about something which worries you.

#### **EXAMINE ALL AREAS OF YOUR BODY**

• You must look everywhere on your body. Although sun exposure increases the risk for melanoma, the disease is not limited to sun exposed skin.

#### **GET HELP**

• Though a lot can be achieved by looking at yourself in a mirror, it is best if you have a partner assist you with the check.

#### **COMPLETE YOUR SELF SKIN EXAMINATION RECORD**

## SKIN SELF EXAMINATION RECORD

	Date							
Area								
Scar & surrounding skin								
Face, scalp & ears								
Neck & shoulders								
Back, chest & abdomen								
Genitals & buttocks								
Legs, front & back								
Between toe & finger spaces								
Fingernails & toenails								

## THE LYMPH NODES

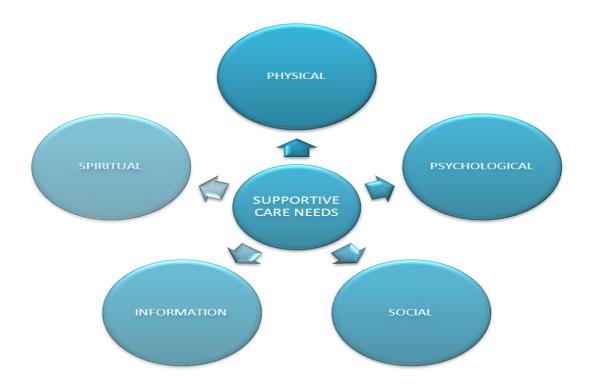
Melanoma cells may travel to the lymph nodes and cause them to swell to a size resembling a marble or a grape and to feel tender, though "palpable" lymph nodes may also be normal or a response to infection. The important places to check are the neck, the armpits and the groin.

# OTHER IMPORTANT SYMPTOMS

The following is a general list of symptoms that you should tell your doctor about. However, every individual is different so seek advice from your doctor if you have any questions or concerns about symptoms that are not on this list.

- New headaches
- New bone pain
- · Difficulty breathing
- Abdominal pain or swelling
- Weight loss without intention

## SUPPORTIVE CARE



The diagnosis of melanoma may impact on many aspects of your emotional and personal wellbeing. The next pages are a "supportive care screening tool". This is a set of questions you pose to yourself to help organise your thoughts about this.

The screening tool for measuring distress can be used to help identify any issues and concerns which you may have at any time during your cancer journey. Please use this tool to prompt discussion with your health care provider.

If you find your "score" on the distress thermometer is more than 4, or you have identified specific areas of difficulty in your life, you should immediately ask your doctor to help you directly or by referral to others.

It is recommended that you consider completion of this screening tool every 3 months in the first year after your initial diagnosis or any episode of disease recurrence.

Distress score/Specific issues	Help sought from
	Distress score/Specific issues

Screening date:					tress Mana cology. Nat 0. Available 0. To view	igemer ional ( e at ht the m	nt Clini Compre tp://ww ost red	from The NCCN® 1.2010 ical Practice Guidelines in ehensive Cancer Network, w.nccn.org. Accessed July cent & complete version of www.nccn.org.	
	actice Guidelines Oncology - v.1.2008		Please indicate if any of the following has been a problem for you in the past week including today.						
Instructions			Be sure to tick YES or NO for each						
1. Please circle the (0-10) that best de		Yes	No	Practical Pro				Physical Problem	
much distress you	ı have been			Child care				Appearance	
experiencing in the including today.	e past week			Housing				Bathing/Dressing	
				Insurance/Fina	ancial			Changes in urination	
				Transportation	1			Constipation	
				Work/School				Diarrhoea	
Extreme distress	10							Eating	
	9 -   -	Yes	No	Family Probl	ems			Fatigue	
	8 —   —			Dealing with c	hildren			Feeling swollen	
	7 -  -			Dealing with p	artner			Fevers	
	6 —							Getting around	
	5 —	Yes	No	<b>Emotional Pr</b>	oblems			Indigestion	
	4 -   -			Depression				Memory/concentration	
	3 —			Fears				Mouth sores	
	2			Nervousness				Nausea	
				Sadness				Nose dry/congested	
No distress				Worry				Pain	
No distress				Loss of interes				Sexual	
		Yes	No					Skin dry/itchy	
				Spiritual religi	ious			Sleep	
				Concerns				Tingling in hands/ feet	
Have you previously had treatment for emotional problems: YES NO  (e.g. anxiety/depression)									

4 = Mostly

5 = Completely

3 = Moderately

2 = A Little

Screening date:					tress Mana cology. Nat 0. Available 0. To view	igemer ional ( e at ht the m	nt Clini Compre tp://ww ost red	from The NCCN® 1.2010 ical Practice Guidelines in ehensive Cancer Network, w.nccn.org. Accessed July cent & complete version of www.nccn.org.	
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# **INFORMATION DIRECTORY**

	SKIN CANCER AND MELAN	OMA
Victorian Melanoma Service The Alfred Commercial Rd Prahran VIC 3181	Phone: (03) 9530 5940	www.victorianmelanomaservice.org
Melanoma Patients Australia	Phone: 1300 88 44 50 info@melanomapatients.org.au	www.melanomapatients.org.au/
Melanoma Institute of Australia P.O. Box 1479 Crows Nest NSW 1585	Phone: (02) 9911 7200	www.melanoma.org.au/
ANZ Clinical Practice Guidelines for the Management of Cutaneous Melanoma		www.nhmrc.gov.au/_files_ nhmrcpublications//cp111.pdf
	SUN SAFETY	
Sunsmart Australia 1 Rathdowne Street Carlton Victoria 3053	Phone: (03) 9635 5148 SunSmart@cancervic.org.au	www.sunsmart.com.au/
CAN	ICER COUNCILS & ORGANI	SATIONS
Cancer Council Australia GPO Box 4708 Sydney NSW 2001	Phone: 131120 info@cancer.org.au	www.cancer.org.au/
Cancer Council Victoria	Phone: (03) 9635 5000 enquiries@cancervic.org.au	www.cancervic.org.au/
Canteen (Australian Organization for Young People Living with Cancer) PO Box 63 Parkville VIC 3052	Phone: (03) 9912 4221 vic.admin@canteen.org.au	canteen.org.au/
Australian Cancer Survivorship Centre	(03) 9656 1111 Contactacsc@petermac.org	petermac.org/cancersurvivorship/home
	HOSPITALS	
The Alfred PO Box 315 Prahran VIC 3181	(03) 9076 2000	www.alfred.org.au/
Peter MacCallum Institute Locked Bag 1 A'Beckett Street VIC 8006	(03) 9656 1111	www.petermac.org/
Peninsula Health PO Box 52 Frankston Vic 3199	(03) 9784 7777	www.peninsulahealth.org.au/
Austin Hospital 145 Studley Rd Heidelberg 3084	(03) 9496 5000	www.austin.org.au/
REI	EVANT MEDICAL ORGANIS	SATIONS
Australasian College of Dermatologists PO Box 3785 Rhodes NSW 2138	1300 361 821 (Australia only) admin@dermcoll.asn.au	www.dermcoll.asn.au/
Skin and Cancer Foundation Victoria	(03) 9623 9400 info@skincancer.asn.au	www.skincancer.asn.au/