

LOOKING AFTER YOURSELF AFTER MELANOMA

Coping

Sometimes the speed at which everything happens can feel overwhelming.

You may feel as if you are in your doctor's surgery one day and waking up after an operation the next. This speed does not give you very much time to deal with your feelings in any depth. Sometimes you can only begin to think about the emotional issues after the initial treatment has been completed. It is only then that you are able to take the time and have the energy to begin to look at things in any detail.

Some people worry that they do not know how to cope with a diagnosis of cancer. This is not surprising.

The word cancer frightens nearly everyone. Most of us do not have past experience to draw on to help us and the speed and ever-changing challenges make it difficult to have a clear plan of action.

As there is no one standard set of reactions to the diagnosis, so there is no standard way of coping. We will all find our own way.

However, there are some general points that you might find helpful. Difficult though it is, confronting and being open about your feelings is a good place to start.

It is often helpful to be able to share these feelings with a trusted friend – someone who is not going to tell you to pull yourself together or to stop being silly. The sort of friend who will listen without judging, be with you and not interrupt, to support without interfering. Simply 'getting things off your chest' is all that you may need. Some of you will find it helpful to talk to someone outside of your family or friends – your doctor or specialist nurse, a counsellor or psychologist.

They are there to help you, to support you, so do not be afraid to ask if that's what you think you need.

LOOKING AFTER YOURSELF AFTER MELANOMA

Sun protection

It is sensible to reduce sun exposure for you and your family, because the main causal factor for melanoma is the sun. This is particularly sensible advice if you and your family are moley, especially if they have the Atypical Mole Syndrome (AMS) – lots of moles.

It is also particularly sensible if you and your family are fair skinned: if you burn in the sun, if you have red hair or freckles.

- The best advice is to keep out of the sun but this does NOT mean you cannot go on holiday. Have fun but come home pretty much the same colour as you went.
- Keep out of the sun when it is most strong: between the hours of 11.00 am and 3.00 pm. Seek the shade then: have a lovely lunch. Arrange to go out early morning and late afternoon.

- Use the shade. Trees, umbrellas and buildings all give shade throughout the day from buildings as the sun moves round.
- Leave your shirt on! Avoid strappy tops which leave the shoulders exposed.
- Hats give good protection to the face, neck and ears (particularly important for people with short hair). 4 inch brims are desirable: the more popular baseball caps are less valuable because they do not protect the neck and ears.
- Sunblock is useful for the skin which cannot be covered, but it is not the be-all and end-all of sun protection. Use waterproof sun block with an SPF (Sun Protection Factor) of at least 15, and 4 to 5 stars UVA protection.

Advice about sun protection is available from the SUNsmart campaign
www.sunsmart.org.uk

LOOKING AFTER YOURSELF AFTER MELANOMA

What else should I do to my lifestyle?

There is no evidence that doing anything else is important.

Patients often ask about diet and alcohol and reasonable advice would be to eat a healthy diet (as we should all do) with five or more portions of fruits or vegetables a day. Beyond that, moderation seems sensible advice but the maxim that “a little of what you fancy does you good” also seems appropriate.

Some people react to the diagnosis of melanoma by re-assessing their life and their life-style generally. Some try to achieve a ‘better balance’, which also seems sensible. Some decide to take that special holiday.

LOOKING AFTER YOURSELF AFTER MELANOMA

Looking after yourself

Keep an eye on your moles: see the leaflet “Looking after your moles”

Examining your lymph glands

The lymphatic system

Lymph glands are part of the lymphatic system.

The system is made up of tiny channels called “lymphatics”. These channels drain fluid from the skin and other tissues back into the blood, passing the fluid through the lymph glands on the way. This system is part of the immune system: that is that this movement of fluid is important in defending against infection and cancer.

However the commonest way that melanoma may spread is within the lymphatic channels. Cells may travel within these channels settling in the nearest lymph gland where they can grow and show up as a swelling.

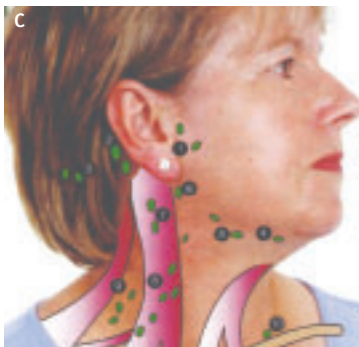
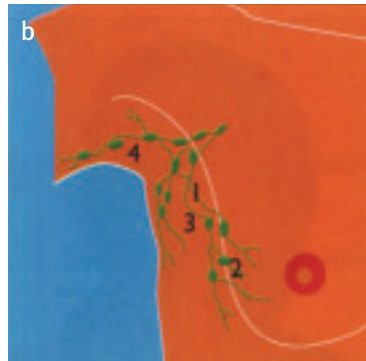
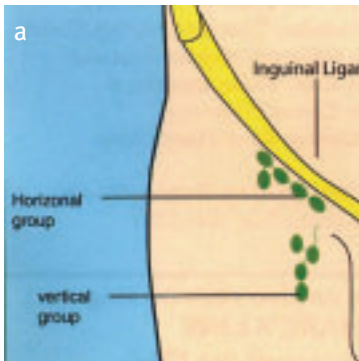
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Looking after yourself

Examining your lymph glands

The lymph gland in which a swelling is most likely to occur is to some extent predictable. Melanomas on the leg usually produce lumps in the groin(a). Melanomas on the arm usually produce lumps under the arm(b), and melanomas on the trunk

(back or chest) may produce lumps in the groin or under the arm. Melanomas on the head usually produce lumps in the neck(c). These lumps are enlarged lymph glands in which melanoma cells are growing.



These images shows where the lymph glands are.

Pictures used with the kind permission of Denise Hancock and the Wessex Cancer Trust.

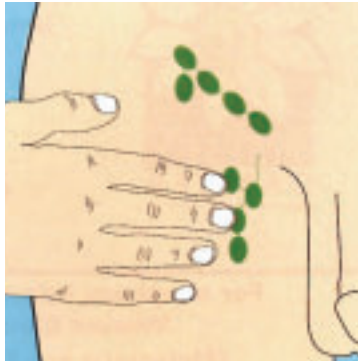
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What should I do if I develop swollen lymph glands?

If you think you have a swollen lymph gland, telephone your melanoma clinic or GP.

Don't worry at home: get the gland checked.

Often patients are feeling entirely normal glands, which have come up because they have had an infection, banged their toe etc.



These images shows how to examine lymph glands.

Pictures used with the kind permission of Denise Hancock and the Wessex Cancer Trust.

FREQUENTLY ASKED QUESTIONS

Will I need other tests?

Will I need any tests after my operation?

After a melanoma has been removed from the skin, patients are followed up in clinic in order to pick up a recurrence of that melanoma should it occur.

The majority of melanoma patients never have a recurrence, but some do. The most common place for the melanoma to recur is as a swollen gland as discussed in Looking after yourself after Melanoma – Examining your lymph glands.

The best way to find swollen glands is by physical examination. Follow up in clinic is usually by thorough examination rather than by tests such as scans.

Some patients will have a chest x-ray and a blood test. These tests may be used as a baseline so that later if you have symptoms (for example a cough) it will be helpful to have a previous chest x-ray to compare with. They are not however essential.

Is a routine scan required after my melanoma is removed?

Some patients seek the reassurance of a normal scan and it is reasonable to discuss this with your doctor.

However, scans can cause more trouble than they are worth. It is very unlikely that a scan will show any abnormality soon after a melanoma has been removed. The scan may however show minor abnormalities, which cause confusion: around a quarter of people have cysts etc on their scan, which cause anxiety even though they are harmless.

This can of course be very worrying and it will require a second scan later to resolve the doubt.

Furthermore body scans expose the body to a fair dose of radiation and should therefore only be used when there is good reason to do so.

FREQUENTLY ASKED QUESTIONS

Will I need any tests after my operation?

Scan – Summary

Generally speaking whether you should have a scan should be decided by you and your doctor, balancing the following:

- The risk of the melanoma coming back. Most melanoma patients have a low risk of the melanoma ever returning. If the risk is higher, for example if melanoma has developed in a swollen gland, then a scan may be sensible.
- The presence of any symptoms, such as sickness, or pain.
- The negative aspects of having a scan such as detecting harmless changes in a significant percentage of patients.
- The dose of radiation.

What is the purpose of follow up?

Follow up

It is routine practice to follow up patients in a hospital clinic in the UK for 3 to 5 years after diagnosis.

The frequency of follow up is normally three monthly, although initially it may be more often.

The purpose of follow up is as follows:

- To detect a recurrence of the melanoma, should it develop.
- To examine the skin.
- To support the patient through diagnosis and afterwards.

NEW TREATMENTS FOR MELANOMA UNDER EVALUATION

What is sentinel node biopsy?

If melanoma recurs, it usually comes back in a swollen gland. Sentinel node biopsy is a technique used to look for melanoma cells in the lymph glands early, before the swelling can be detected. Its role is still being evaluated

In this operation, a blue dye and a radioactive tracer are injected around the scar where the melanoma was removed.

The dye and tracer are then followed to the nearest lymph gland, which is called the “sentinel node”. This is the gland that the melanoma is most likely to drain to, and therefore the most likely to contain melanoma.

This gland is then removed during an operation.

If a melanoma is removed from the leg then the sentinel node is usually in the groin. If the melanoma was on the abdomen, then the sentinel node could be in the groin or under the arm.

Pathology of sentinel node biopsy

During the following week the pathologist will look carefully at the removed lymph gland, under the microscope, for tiny deposits of melanoma. These are often referred to as micro-metastases.

If these are detected then the doctor would normally recommend that all of the glands in the area are removed: this is known as a lymph gland dissection.

If the sentinel node biopsy is negative, it is reassuring because it means that there is less chance of further trouble from the melanoma. It does not mean that the melanoma will not come back: but the chances are much lower.

FREQUENTLY ASKED QUESTIONS

What is sentinel node biopsy?

How useful is sentinel node biopsy?

Although sentinel node biopsy seems like a good idea, there is no evidence that removing the glands early in this way has any effect on the chance of the melanoma coming back. Furthermore the injection of the dye and tracer and the removal of one gland is associated with some symptoms. Therefore in the UK the current consensus is that the operation is not of proven value.

It is important to continue to assess its value and it is very possible that views may change but to date sentinel node biopsy remains an operation that is under evaluation. Sentinel node biopsy may have a more valuable role ultimately in selecting patients for treatment.

When there is an effective way to reduce the risk of recurrence of melanoma such as a vaccine, then sentinel node biopsy may be used to help choose which patients should be offered that treatment. (Although vaccines are already being investigated in clinical trials, we do not yet know if they work.)

FREQUENTLY ASKED QUESTIONS

What is interferon?

Interferon

It is very desirable to find additional means of reducing the chances of the melanoma coming back.

Many people have looked at a range of different treatments to see if this can be done. Most of these studies have been done in patients who have a higher risk of the melanoma coming back, such as people who have had their lymph glands removed because of spread, or who have very thick melanomas. The treatment that has been looked at most in this situation is interferon.

Interferon is a substance which your own body makes in response to “flu” and in some situations has been found to improve the immune response against cancer cells: That is, to help the body to defend itself against the cancer. As a medicine it is given in much larger quantities than the body produces for itself. It is given as an injection 1–3 times a week and does have significant side effects: it makes people feel as if they have flu, although this does tend to settle over the first few weeks of treatment. Interferon may cause inflammation of the liver or suppress the bone marrow.

FREQUENTLY ASKED QUESTIONS

What is interferon?

Clinical trials of Interferon

Although the clinical trials of interferon were initially very encouraging, the recent ones have failed to show a clear advantage to using it for melanoma to prevent a recurrence. In the UK the consensus is that its role is unproven.

There are however several clinical trials that are running which are looking at different schedules of interferon or different ways of giving it to determine if it can be useful.

In Europe interferon has been tried within clinical trials, for patients whose melanoma has come back as a swollen lymph gland.

If you have had a lymph node dissection your doctor may talk to you about clinical trials, shortly after the operation, if they are available.

What is a clinical trial?

A clinical trial is a study designed to see whether a treatment works or not. The best way to find this out is to carry out a randomised clinical trial.

The patient is counselled about the trial and if they choose to take part a computer then “decides” whether they will receive the trial treatment or not. That is, the decision as to whether the patient has trial treatment is made randomly by the computer.

Most of these studies will be comparing the effect of treatment with observation. That means that half the patients in the study will undergo follow-up with observation (as is normal practice) and the other half will undergo the experimental treatment. In other studies, the trial treatment will be compared with a standard treatment.

Rarely, the patients who do not receive the active treatment will receive a placebo: a harmless but ineffective injection or pill.

FREQUENTLY ASKED QUESTIONS

What is a Vaccine

Vaccines

Attempts are also being made to reduce the chance of melanoma coming back by boosting the immune system using a vaccine.

Although vaccines seem a logical thing to try, so far there is no proof that they work.

Various vaccines are in clinical trials around the world.