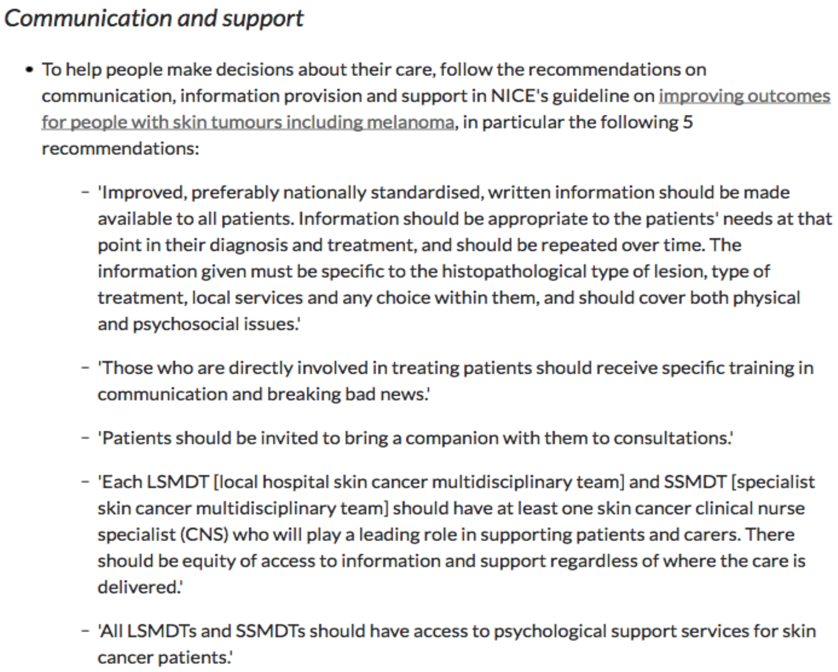
The value of psychological support

JULIA NEWTON-BISHOP

Is there a need for psychological support for melanoma patients?



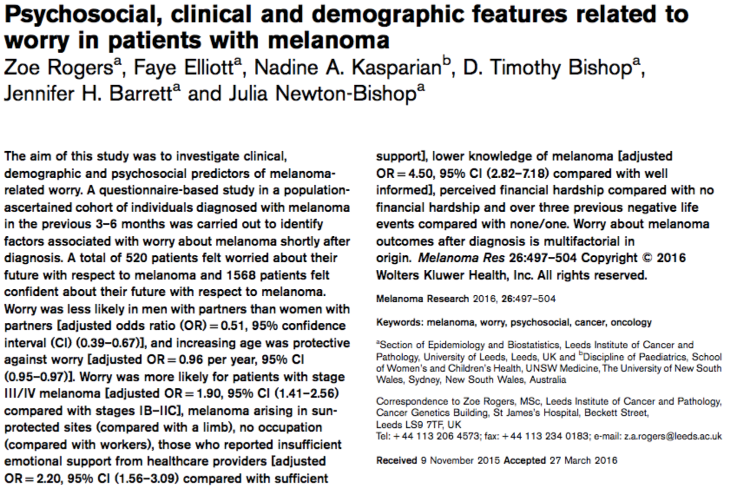
Communication and support

- To help people make decisions about their care, follow the recommendations on communication, information provision and support in NICE's guideline on improving outcomes for people with skin tumours including melanoma, in particular the following 5 recommendations:
  - 'Improved, preferably nationally standardised, written information should be made available to all patients. Information should be appropriate to the patients' needs at that point in their diagnosis and treatment, and should be repeated over time. The information given must be specific to the histopathological type of lesion, type of treatment, local services and any choice within them, and should cover both physical and psychosocial issues.'
  - 'Those who are directly involved in treating patients should receive specific training in communication and breaking bad news.'
  - 'Patients should be invited to bring a companion with them to consultations.'
  - 'Each LSMDT [local hospital skin cancer multidisciplinary team] and SSMDT [specialist skin cancer multidisciplinary team] should have at least one skin cancer clinical nurse specialist (CNS) who will play a leading role in supporting patients and carers. There should be equity of access to information and support regardless of where the care is delivered.'
  - 'All LSMDTs and SSMDTs should have access to psychological support services for skin cancer patients.'

The NICE Clinical Melanoma Guidelines

https://www.nice.org.uk/guidance

How many patients worry significantly after a melanoma diagnosis?



Psychosocial, clinical and demographic features related to worry in patients with melanoma

Zoe Rogers[a], Faye Elliott[a], Nadine A. Kasparian[b], D. Timothy Bishop[a], Jennifer H. Barrett[a] and Julia Newton-Bishop[a]

The aim of this study was to investigate clinical, demographic and psychosocial predictors of melanoma-related worry. A questionnaire-based study in a population-ascertained cohort of individuals diagnosed with melanoma in the previous 3–6 months was carried out to identify factors associated with worry about melanoma shortly after diagnosis. A total of 520 patients felt worried about their future with respect to melanoma and 1568 patients felt confident about their future with respect to melanoma. Worry was less likely in men with partners than women with partners [adjusted odds ratio (OR) = 0.51, 95% confidence interval (CI) (0.39–0.67)], and increasing age was protective against worry [adjusted OR = 0.96 per year, 95% CI (0.95–0.97)]. Worry was more likely for patients with stage III/IV melanoma [adjusted OR = 1.90, 95% CI (1.41–2.56) compared with stages IB–IIC], melanoma arising in sun-protected sites (compared with a limb), no occupation (compared with workers), those who reported insufficient emotional support from healthcare providers [adjusted OR = 2.20, 95% CI (1.56–3.09) compared with sufficient support], lower knowledge of melanoma [adjusted OR = 4.50, 95% CI (2.82–7.18) compared with well informed], perceived financial hardship compared with no financial hardship and over three previous negative life events compared with none/one. Worry about melanoma outcomes after diagnosis is multifactorial in origin. ***Melanoma Res*** **26:497–504 Copyright © 2016 Wolters Kluwer Health, Inc. All rights reserved.**

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2184 patients interviewed within the first year after diagnosis

How do you feel about the future with respect to the melanoma?

75% (n=1568) reported confidence about the future and 25% of participants (n=520)reported worry

Men were 50% less likely to report worry

Worry was less likely for every year increased age

Patients with stage III/IV were more likely to be worried than earlier stage patients

Patients with melanomas in unusual sites worried more eg vagina or under the nail

General conclusions

Individuals who worried more about the future may do so because of the cumulative effects of stress (disease and non-disease related)

That a perceived lack of support from healthcare teams generally makes this worse

Previous anxiety/depression increased the risk of worry

Patients with a high internal locus of control were less likely to worry

What gets patients down?

Supportive Care in Cancer

March 2015, Volume 23, Issue 3, pp 779–789

Assessing the impact of diagnosis and the related supportive care needs in patients with cutaneous melanoma

Authors

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Zoe Stamataki, L. Brunton, P. Lorigan, A. C. Green, J. Newton-Bishop, A. Molassiotis

16 patients within 5 years of a melanoma diagnosis

Stage I to III melanoma

Semi-structured interviews lasting a mean of 54 mins

4 major themes emerged

- Emotional effects
- Effects on relationships
- Functional effects
- Health care system and information needs

Uncertainty about the future

- *"Am I now waiting for something else to go wrong? It seems like you are waiting for your future. Its probably the same with any cancers but with melanoma you're thinking now I can only be vigilant, I can only look for moles and lumps… I just feel that with this you're looking for things that can be wrong (male stage III)*

- *"I feel a bit crap today and all that. But you can't I mean if you knew somebody on the phone or you were going to cancer hospital and you could have half an hour…. But there's nothing, you're just out on a limb really. Even though it's a cancer, there's no actual help"*

Altered body image

Reported problems relating to wide excision scars, lymphoedema or nodal surgery

For some patients the feelings seemed to relate to expectations: they didn’t expect the scars to look so bad

Some said they tried to cover up the scars (avoiding bikinis etc)

Another that she thought that the perception of the scar contributed to her not finding a partner

Fear of the sun

“ I’m scared to death now to go in the sun unless I’ve pretty much a paste on my skin”

“No specific information from the guys here in the hospital, which is something that I would have thought they would have handed out as a matter of course….. Like here is what you can and cannot do....

Effects on relationships at work

- Feelings of embarassment that he illness had meant that they could not perform their work in the same way as before
- Lack of support from colleagues or bosses
  - One had heard comments like “oh, he’s always off sick”
  - One felt that her bosses didn’t take it seriously
- One person actually felt better about his job after the cancer diagnosis and actually that helped his relationship with his wife as previously he had often complained to her about his job

“ It annoys me … but I don’t want to apologise ….. But I do feel, although I am wrong to do so, like I said “Oh I only had skin cancer” You almost feel that you should have a better one... I came third in the race...”

“ Shouldnt we have an advert, melanoma patients”

Effect on relationships at home

Some patients reported good support and positive feelings about that support

Others reported they were mindful of not discussing their fears for fear of pushing the family member away or to protect them

“I don’t want to be seen as someone that’s always complaining and always down”

Health care system and information needs

Poor quality of information

- *“when I go to clinic I don’t seem to be picking up just what the situation is. What will happen next?”*
- *“ but it’s all these stages and we didn’t have a clue… but you couldn’t ask anybdoy, you know, go back to them and say: cause you dont want to tell people that I went to clinic today and they said stage 3 and I dont know what it means”*

Patients benefitted from time with the specialist nurses especially if it was soon after the diagnosis “ three months later is too late”

Not enough time “it’s almost a case of ‘right, turn, right, on the bed let’s look at your leg. Oh that’s fine, you know, poke poke, poke in the groin for any ... Swelling of the lymph nodes and ‘okay you’re fine come back in three months”

Summary so far

Around 25% of patients diagnosed within 1 year of diagnosis feel worried about their future

The worry was greater with more advanced disease

Worry was reported less by men, less by the older patients (unless they were ?lonely)

Worry was often worse where its “the final straw”

Worry also more common for melanoma in unusual sites

Issues reported in interviews were:-

Uncertainty about the future

Changed body image

Fear of the sun

Effects on relationships at work

Effects on relationships at home

Loss of my “normal life”

Perceived lack of support from the hospital

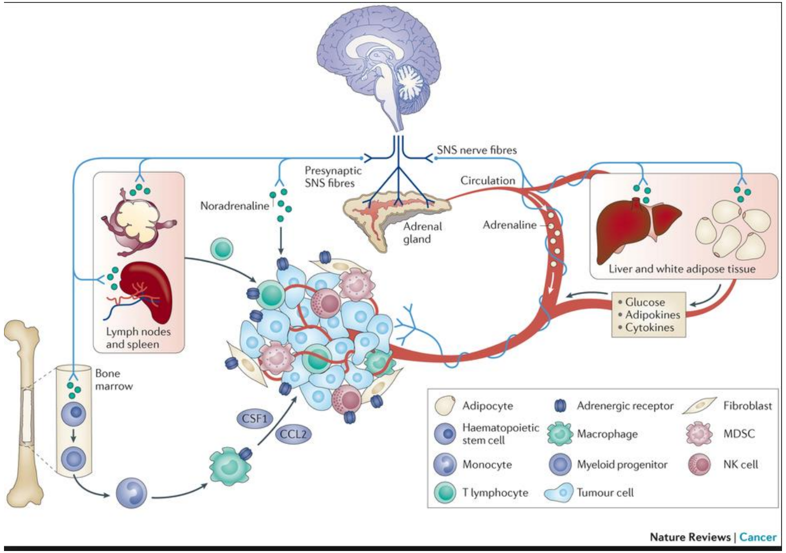
Coping

- Adjustment
- Resilience
- Emotional well-being

“Patients use different strategies at different times depending on their own changing circumstances, their relationships ..”

Keier et al Surg Clin N Am 2003

There is some evidence that chronic stress is harmful to health so that it intuitively seems right to support coping strategies



Nature Reviews | Cancer

What are patients trying to achieve emotionally? Proportion and balance

"Ideally a patient would experience a degree of hope that was proportional to the positive survival chances that applied, but would also experience a degree of worry and emotional upset that was proportional to the mortality rate in similar cases"

Health care professionals can help by acknowledging this balance

Keier et al Surg Clin N Am 2003

Coping Strategies: Kneier et al 2003

Facing the reality of one’s illness
- Confronting the full reality
- Denial
    - Sometimes helpful as it protects: allows a step by step approach
    - But for many leads to failure to adjust in the long term

Maintaining hope and optimism

Reported to be associated with better outcomes

- But really difficult to evaluate this
- And people vary enormously in how able they feel to be optimistic
- Even feel guilty that they cannot be optimistic

Patients often feel that it is wrong and dangerous to feel optimistic

Expect the Worst but Hope for the Best

Posted by Daniel De Guia

This post started about a year ago. Many times I wrote the post and then edited it. Each time, it wasn't what I wanted it to be and the goal of the post became too muddied with side tangents. So I shelved on the post. It collected dust in my Drafts folder, until the time came where I decided to tackle it once more. Rinse; repeat.

I'm often referred to, usually half-jokingly, as a grump or a pessimist. Those comments usually spur on a friendly debate on pessimism vs. optimism vs. being realistic.

Growing up, my dad always used to say, "Expect the worst but hope for the best." That was his way of teaching my sister and I to go forth into life's experiences, planning and preparing for the worst-case scenario, but hoping (aka: praying) for the best.

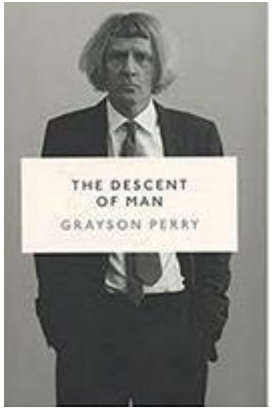
Expressing one’s emotions

Helpful because it gives the person an outlet for his/her feelings, a means of working them through and an opportunity to obtain better support

Some people are not practiced in attending to their own feelings

If health care professionals trivialize a patient’s distress then the patient learns to avoid expressing that distress

In our society men might find this more difficult



Reaching out for support

People who are largely alone or find it difficult to avoid reaching out tend to make a poorer psychological adjustment

Some pride themselves on being self-sufficient

Some don’t like the kind of “cheerleading” kinds of support

Support groups may help some people

“Taking control”

A person with belief that he or she is an active and effective person with “self-efficacy”

Adopting healthy behaviours may help fight the cancer as well as helping us to deal with the emotions

- Exercise
- Healthy diets
- No smoking

Health care professionals can help by overcoming passivity

Picture Quotes

Counting one’s blessings, spirituality

Some people try to relish all the positive aspects of living: they no longer feel they take life for granted

Feeling closer to family and friends

You know it took me a while to se but some good things have come out of it

Faith helps some

Even when its difficult to understand why a loving God allows these things to happen…..“When bad things happen to good people” Rabbi Kushner

Maintaining self esteem

Bodily changes make it difficult

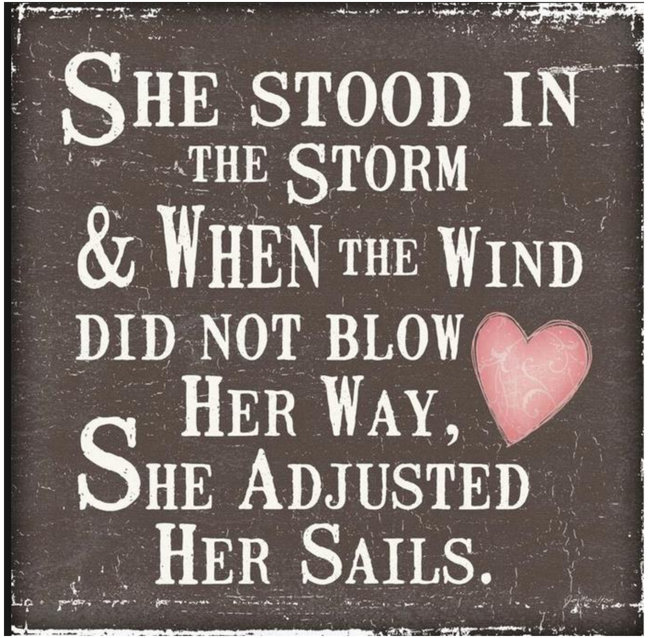
Inability to do the things that are improtant to us:-

- Work
- Physical activity
- Being independent

Hanging on to normal life

Keeping cancer in its place

Embrace new sources of self esteem



She stood in the storm & when the wind did not blow her way, she adjusted her sails.

Pinterest

Coming to terms with mortality

Touchy: should we ever accept death?

To achieve a sort of peace

Facing the possibility of death earlier rather than later has been found helpful by some: it may enable the person then to go forward living a fuller life.

Planning For Your Own Death

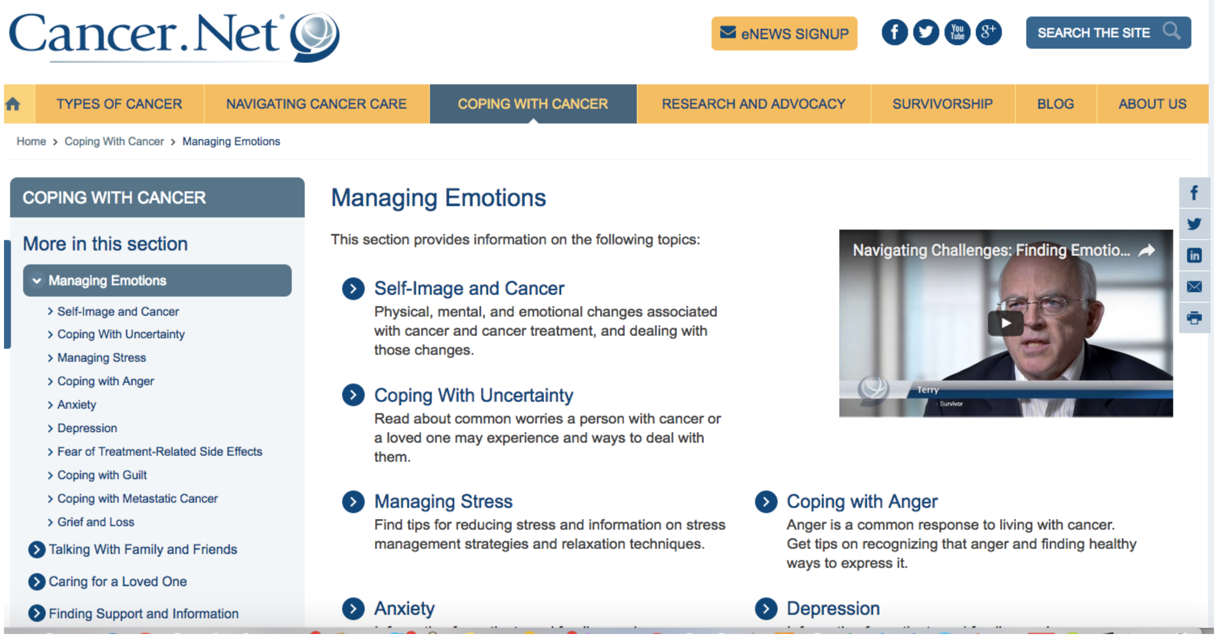
If you are reading these words, the day will come when you will die. Usually death comes expectedly, at the end of a long, well-lived life or at the end of a terminal illness. But on occasion, death arrives without warning. Accidents, sudden illness, even becoming the victim of a crime can cause you to die without notice, without time to plan.

Don't be caught unprepared.

Download our checklist, and allow our guidance to give you peace of mind.

If you would like to stay updated with our latest insights, newsletters and blogs please fill out the form below now.

"Preparedness brings peace"



Managing Emotions

This section provides information on the following topics:

Self-Image and Cancer
Physical, mental, and emotional changes associated with cancer and cancer treatment, and dealing with those changes.

Coping With Uncertainty
Read about common worries a person with cancer or a loved one may experience and ways to deal with them.

Managing Stress
Find tips for reducing stress and information on stress management strategies and relaxation techniques.

Coping with Anger
Anger is a common response to living with cancer. Get tips on recognizing that anger and finding healthy ways to express it.

Anxiety

Depression