

Kathie Godfrey -

Hello everyone and thank you for inviting us to speak to you from a Consumer viewpoint.

Hola y les agradecemos el habernos invitado a dar la perspectiva de los consumidores en esta reunion.

We had several ideas about this presentation but finally decided that each of us would spend a few minutes talking about our interest in skin and how it brought us to the Cochrane Collaboration in general and the Skin Group in particular.

I confess to having taken my skin completely for granted. In company with many youngsters, my face was a mass of freckles, so much so that it led one schoolmaster to tell me that I looked as though someone had flicked mud at me! I was a happy-go-lucky sort of kid and accepted the situation without second thoughts. In my ignorance, I continued to think of skin as merely an outer casing that kept the body together!

In 1984, a mole on my ankle had changed and whilst I suspected this was a skin cancer I did not think this could be a serious problem. After all, I still believed that the skin was just an outer shell with nerves that responded to inflicted pain and bled when wounded - not really connected to anything vital in the rest of the body and I had worse health problems than that to worry about! In 1986, I had a hysterectomy and the gynaecologist recommended that I got the mole checked out - good advice but bad timing! My family finally nagged me into consulting a GP, who dismissed it as not a problem but later, a colleague of his spotted it and insisted on referring me to a dermatologist. This was when I made the shocking discovery that skin was actually an important organ when I was diagnosed with malignant melanoma - something I had never even heard of, yet alone envisaged as happening to me! The diagnosis and the prognosis were delivered without frills and two days later, I was admitted to hospital for removal of the offending object. For nearly four years, everything seemed to be progressing well until I discovered a lump in my groin, so it was back to hospital for surgery to remove the node and drain the lymph system. This was a great shock to me and to my family. This was really serious stuff, not just an unfortunate occurrence, like the initial melanoma!

When I first met the dermatologist, he left me with the distinct impression that I should have known better - both in preventing the problem and in recognising it once it had occurred! This idea stayed with me and formed the basis of my inclination to get involved in some way of helping to enlighten others at risk. Among other things, I wrote articles on sensible sun exposure (some were published) and featured in an article on sun awareness in the local paper. The headmistress of my grandson's pre-prep school read the article and promptly ordered baseball caps for all the pupils - my "finest hour"! However, evangelising is a thankless task and I knew there had to be a better way of helping people to understand.

When I was finally cleared some nine years later, that was another concept that took some getting used to. At first, it felt as though a lifeline had been withdrawn but I gradually became accustomed to the realisation that once again, I was responsible for my own well-being.

I responded to an advertisement in the local paper for volunteers to carry out hand searching for the Cochrane Collaboration Gynaecological Cancer Group. This seemed to offer an opportunity to repay my debt for the excellent medical care

I'd received. After some initial training, I began a three year stint of hand searching clinical trials for inclusion in the Cochrane Register. Once this was up to date, I went on to provide consumer comment on protocols & reviews for the Group. I attended my first Colloquium in Lyon where I joined up with the Skin Group. Tina subsequently enrolled me as consumer advocate for a review on treatment of malignant melanoma and now I provide consumer comment for several Cochrane Groups.

I have been an active member of the Consumer Group for the past six years, during which time the Group has evolved into a Cochrane Network which contributes much to the Collaboration and its Groups as well as to the whole concept of consumer involvement in decision making. On this subject, in the last 2 or 3 decades there has been a big change in the relationship between practitioners and patients. Now, patients are offered choices - type of treatment and even whether to treat or not! Of course, this is a great step forward but it would be so much better if these choices were made on an informed basis.

It was probably more comfortable to believe that "doctor knows best" and leave one's fate in the lap of the Gods! Luckily for me, one doctor knew better than another or I might not have been here today enjoying your company! Nowadays, however, patients or carers have to take some responsibility in the decision making process.

No-one is infallible and no matter what our training and qualifications, we all make mistakes. Possibly, it isn't universally popular with professional clinicians and researchers that non-qualified people can question their judgement but this is true democracy. None of us are professional politicians but we all believe in an inalienable right to express our opinions and make decisions at the ballot box! Cochrane consumers firmly believe that they can and do make a valuable contribution to the improvement of health consumers worldwide.

Consumers have to absorb this concept of decision making in health matters and practitioners have to assume the role of mentor as well as expert. As consumer contributors to the Cochrane Collaboration, I hope that we can help to take this partnership forward.

Thank you for listening. I would now like to hand over to Maxine to tell you of her experiences.