

Cancer - The patients voice

European Parliament, Brussel – ESMO Policy Briefing:

The Fight Against Cancer – Where Next?

10th November 2009 - by Anita Waldmann, President of MYELOMA EURONET

Cancer in general is not rare already for long time. But there are still some of very rare types like Myeloma is one of them.

Everybody in this room will have direct experience either themselves, by relatives, by friends or colleagues having cancer during their lives.

Every family in Europe is touched in some way by this devastating disease.

We live in an era of profound and rapid techno-logical change and yet still - for many of us - lives and families - are ruined through the plague of being struck down by a disease, the mere name - of which is almost unspeakable for many - It becomes the 'big C'..

Today in Europe

thousands of people will be told - that they have cancer.

But - cancer is no longer an instantaneous death sentence. The big hope today is - that we will live with cancer for many months and years and that we will go - from one remission to another.

I have been asked to speak today about cancer from the perspective of the patients. And I'm very happy to have this special opportunity.

There are three key themes - I want you - to remember from what I have to say today.

The first one is **TIME**

Cancer from a patient's perspective is all about time.

- The time we spend to find the right doctor to have a adequate diagnosis,
- The time we have to live
- The time we have to spend with our loved ones
- The time we have to spend each day - visiting doctors, clinics, hospitals, specialists.

And therefore - the time we not longer have to spend in fulfilling any other dreams we might have.

The second theme - I would like you to go away with today is the theme of **INFORMATION**

Many of us are informed patients. This does not mean that we want to be helpless recipients of the latest advertising mantra of the world's pharmaceutical industry.

This does mean - however - that as a cancer patient I am on a quest to know about my disease.

We are searching for the diagnosis, for my prospects, for my treatments, for other patients in a similar situation.

So, for a cancer patient, information has an almost existential quality about it.

Part of our life is literally dependent on 'knowing'.

Thirdly - the final theme - I would like you to remember - is that of **SUPPORT**.

We can not survive alone. The cancer patients needs support and care.

As I said at the beginning that everybody in this room will be touched by cancer - for many of you this means:

you will end up - devoting parts of your lives - to caring for people with cancer.

I had four family members with cancer who died and for two - I cared till the final end!

To repeat - cancer strikes us all - in some way

so - why are these three themes relevant in the European Parliament today?

We need every level of government to act on cancer - I do not think we should be willing to accept the shallow and unambitious logic that says

"Europe does not do health - therefore we should not bother".

On the contrary,

Europe must do health, as citizens and as patients - as carers and as families we need a Europe - where we all have equal access to the best cancer care.

Only through comparing and contrasting across Europe - we will ever achieve this.

27 different kinds of tunnel vision - will not help. Nor do we have the time to wait!

Europe's 'go slow logic' - is not good enough for cancer patients.

The first meeting of Europe's Cancer Partnership 2009 has already been delayed into the New Year. During that delay - probably 200.000 more Europeans will die of cancer. Let us try and remember - that every time we set a deadline for amendments - next month - or every time - we convene a meeting next week (and because of where we are - I am using the language of politics) - during that time real people will suffer in very real ways - because of cancer.

So - bureaucratic inertia is not helpful on top of everything else that cancer patients have to wrestle with.

Next we need to get the information flowing across all over Europe. Europe can add value - in sharing information across the continent, in identifying the best methods of treatment, in establishing networks of care - and in increasing the focus of all of us on prevention (attacking tobacco, alcohol etc...) and early detecting.

Europe must also - slowly and gradually perhaps - to start with add value in the best management of our limited resources. But - as I mentioned before - we also should be aware - that still not every cancer is preventable. And this brings us back to the need for support.

Healthcare - not only cancer - but Healthcare itself, is essentially about the use of limited resources.

As a cancer patient, if I am given a choice - between the politically emotive centralization of healthcare management in Brussels - but done well on the one hand - and the current patchwork of often inadequate care around Europe - especially in some Eastern European parts - it is obvious which I would choose.

Just take the absurd example of palliative care. In many countries in Europe (probably - even in a majority) the concept of palliative care remains unknown. Every where, palliative care services remain inadequate.

This is a perfect example of where Europe urgently needs to invest and to share knowledge and best practice across the continent.

The philosophical arguments about - what Europe **should** and **should not do** are irrelevant.

This institution - this parliament, needs to send a very clear political signal that there is a need for better prevention, better screening and better quality of treatment and care - across Europe.

This can be better achieved through sharing our sovereignty over healthcare resources - than through jealously guarding our hospitals from any 'foreign' influence.

In other words - we need the support of this Parliament and of the European institutions more widely - to build a better Europe for people with cancer.

My Conclusion;

Cancer patients often do not have a lot of time - it is not surprising that we are impatient for change.

Europe can bring change; members of this institution - have not been elected to be bureaucrats.

YOU have been elected for YOUR vision, YOUR ambition and YOUR desire to serve the public.

The view of the cancer patient is very straight forward - we need YOUR commitment and YOUR desire to use the instruments of European public policy to improve outcomes, quality, prevention and the care of people with cancer.