I feel compelled to write a submission on this matter after reading those which reached front page headlines of a national Sunday newspaper. I felt important issues had been missed out, and that certain voices were not being heard.

There is no mention that I have seen that some of these drugs can have, as well as the well-known short term effects, very profound long term effects. It seems this would certainly merit the caution that is being used. There is also an inference in the submissions I have seen that all cancer patients and survivors are desperate for the advancement of and treatment by new drugs, when in my experience this is certainly not always the case.

For some years, since coming across a SIGN guideline highlighting the possible long term risks of cancer treatment in childhood, I have taken an increasing interest in this subject. As somebody who had a supposedly terminal cancer over 50 years ago, after reading this SIGN guide, I realised I really had to learn as much as I could about the possible long term effects of radiotherapy treatment, for reasons of my own health – and the more I learned about possible late effects in general, the more I realised I was very fortunate not to have been treated by chemotherapy as well. What surprised me was in my long years as a health professional, my experience working on a cancer ward, my Edinburgh University degree, I only became aware of these long term risks because I stumbled across a tiny article alerting me to the newly published SIGN76 guideline.

For some years now I have been receiving e-mails on a daily basis from cancer survivors and sometimes their families, from around the world, discussing the troubles they are having with late effects of treatments. In general they appreciate they are lucky to have been treated and to be alive, but it has to be acknowledged that some are left with very profound health consequences as a result of the treatment itself. I appreciate I may be accused of scaremongering, but I have been shocked at some of the stories I have heard. Why is there so little awareness of these possible late and long-term effects of treatments? When doctors must be aware that some drugs can give extremely harrowing long-term results, I think it is concerning that there is no reference to these issues in the submissions. Treatment can indeed be a double-edged sword, cure can come at a cost. I felt so strongly on the matter that I wrote at the start of the year to Dr Mike Richards, the cancer tsar of England, urging him to put further weight on quality of life considerations, when his committees look at new cancer drugs, and spoke to him in June.

There can be profound effects of some chemotherapy drugs which last or even arise many years after treatment. Cardiac late effects can be extreme. Nerve damage, chemo brain, can be extremely debilitating and lead to redundancy; risks of second cancers can be increased. In some sad situations parents can find themselves left to cope alone with a child brain damaged by chemotherapy – a terrifying prospect which they felt totally unprepared for. I am told this set of circumstances cuts them off from help that would otherwise be available to severely disabled children – but because the
child has lived five years past treatment, it is marked as a cure. Certainly many children do indeed flourish after treatment, but it has to be acknowledged that this is not always so. E-mails I have received from the US speak of terrible despair on the part of parents seeing children's mental capacity deteriorate with ferocity years after treatment as a result of the chemotherapy, so that they long even for the child they had at the time of cancer treatment.

I should say at this point that I have been for nearly three years the lay representative of a revival and update of the SIGN guideline on the long term care and support for survivors of childhood cancer – it has gone on for so long as we had to fight to keep the work going when funding was to be stopped. The dedication of the doctors involved in the project deserves a medal. I have been on the committee of PanCare, a Pan European organisation of doctors, researchers, epidemiologists, nurses, survivors, parents etc, with representation from over 26 European countries. PanCare was set up four years ago to raise awareness of the possible long term effects of childhood cancer treatments, to develop and promote follow up guidelines, and to try to improve outcomes. I was asked to be a founding Director of SurvivorNet, a European group for child cancer survivors, and am on the board of Survivors4Survivors, a UK group, set up to support those with late effects. Due to a myriad of commitments I have not been able to give either of these time. Survivors do this in their own time and generally without any funding at all. My family has suffered, but I felt – I feel – there needs to be far more awareness of these issues, for the sake of the patients/survivors involved. The survivor organisations listed above both run – or rather desperately struggle – with virtually no income whatsoever, (one had an initial £500 donation from Macmillan to set up the website, for which we are terribly grateful) dependent on people donating their time. I think this has to be contrasted with the vast wealth of many drug companies and others in the cancer field.

Submissions I have read suggest that all cancer patients avidly wait for the next wonder drug. My experience is that many cancer patients I have spoken to want treatments other than drugs. I have often heard despair that after surgery that is all they feel they are offered. In my experience many would like to see a far bigger emphasis put on issues like diet, exercise, relaxation, and perhaps most importantly, prevention.

The Scottish government has shown its courage in the past with its stance on nuclear, smoking, alcohol. It is time we caught up with other countries in recognising the need for experts in the field of late effects, in addressing the national predisposition to low vitamin D levels, and in concentrating far more on trying to prevent cancers arising in the first place.

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