

Primary Prevention

I feel that the radical change suggested by the committee that women aged less than 70 will not be offered bone mineral density assessment and a treatment in spite of having clinical risk factors is unacceptable and contrary to good practice. Surely good management is about prevention.

A new member of my support group is aged 52 and had no risk factors. However, she had a DXA scan to encourage her friend who is taking prednisolone. My group member discovered that she has a T score of -3.86 SD at the spine. Is she to be refused treatment?

Another member of my group who is a little coy about her age but is well under 70 had pain in her back. She paid to have a DXA scan and this showed that she has a vertebral fracture. Her GP put her on alendronate (Fosamax) and she is happy with this treatment.

The guidelines for people with heart disease and diabetes stress the importance of prevention. Are people with osteoporosis less important?

The World Health Organisation (WHO) tells us that osteoporosis is a disease. Women and their doctors now know that it can be easily diagnosed and treated. NICE appear to be telling us that they are not prepared to invest in preventing the first fracture for women under 70, leaving the NHS to pick up the pieces and the financial burden at a later stage. This defies common sense and is counter to the Royal College of Physicians guidelines that healthcare professionals follow currently.

If people are denied this treatment, I would not be surprised to see the same backlash in the media from people with osteoporosis as is currently happening in breast cancer.

Secondary Prevention

The fact that strontium ranelate (Protelos) is being recommended as an alternative treatment option is very pleasing. The fewer gastrointestinal side effects may help in adherence to the therapy thereby improving the likelihood of successful treatment. This surely will improve the quality of life for many people.

The cost of teriparatide (Forsteo) is a problem but should be considered on a case by case basis, not by age.

A member of my group who is 67 years of age has a bone mineral density of -5.1 SD at the spine, two crush fractures and Crohns disease. She was prescribed teriparatide by her hospital consultant as she is intolerant of all other treatments. It has taken seven months and letters from our MP to get this treatment available for her. This surely is a case where the cost of the drug is effective as her next step would almost certainly be another fracture, hospitalisation and then a care home.

Please remember that when you are talking about populations, you are really talking about individuals whose whole way of life can be changed by a fall and subsequent fractures or simply from bending down causing a spinal fracture.

These individual women want to know that the effective treatments we have to fight debilitating fractures are available.

Patient Representative
21st October 2005