

KLINEFELTER'S SYNDROME ASSOCIATION UK

INFORMATION DOWNLOADS

OSTEOPOROSIS & KS

Paul Collingridge

Aims of this document

The document provides an overview of Osteoporosis and its importance with KS. Please see your doctor/dietician for further details. I recommend you obtain a copy of the booklet:

Compston J (1998) [Understanding Osteoporosis](#) BMA Family Doctor Series (usually available in your local chemist shop/pharmacy, Approx cost £5.00)

Note:

The information contained in this paper has been approved by our Medical Advisers but should not be treated as specific advice to individuals. All such information should be checked with your Health Provider. Drug usage, in particular, is a matter for your Medical Practitioner.

To contact us use any of the following:

Website: <http://www.ksa-uk.co.uk/>

Mail

National Coordinator
Klinefelter's Syndrome Association
56 Little Yeldham Road
Little Yeldham
Halstead
Essex CO9 4QT.

Telephone Contact Number: 0845 230 0047
(Calls charged at local rates)

INTRODUCTION

It is unlikely that anyone visiting this website has never heard of osteoporosis, but to many it is something linked to elderly ladies rather than healthy young boys. However the condition is of particular importance to boys & men with KS, although there is no need for it to be a problem. But ALL of us are vulnerable to the condition, and there is huge gain in adopting a WHOLE FAMILY approach to avoiding the condition through a healthy diet & good exercise. It is predicted that 12000 men each year will need hip replacements due to osteoporosis, whilst 40% of women over the age of 50 will suffer osteoporosis triggered fractures.

How does it happen?

The most vulnerable bones are the long, porous bones with the "honeycomb" centres, as these have the largest surface area, though almost all bones are susceptible. Bone density is managed by two types of cells:

- **Osteoblasts:** fill in the gaps and make bone more dense.
- **Osteoclasts:** break down & reabsorb old bone, creating cavities.

Osteoblasts are most active and dominant in our youth, and are responsive to hormonal, and other chemical, balances in our bodies. It is during this time that we can make the best investment in our future health, by laying down strong bone material and giving every advantage by ensuring our diet, exercise and medication promote bone formation.

Bone mass generally reaches a peak between the ages of 25 - 35 years, and then gradually declines. The worrying part is that bones can deteriorate to a very serious state before any symptoms are felt.

Why is it important in KS?

Testosterone is vital for the production of strong bones in men. Of course, although KS boys often produce very little testosterone of their own, with supplementation this can largely be negated, so it is VITAL that we follow the course of treatment outlined by our endocrinologists. However there are other key factors, such as the low activity levels in some boys, that puts them at risk. Check your family against the list below.

Risk Factor	What to look out for
Genetics	Do you have a family history of fractures due to osteoporosis?
Hormones	Starting testosterone supplements late, regularly missing doses, inappropriate dose.
Diseases	Many diseases, particularly some forms of cancer, can lead to the destruction of bone structure. Unfortunately many treatments are as bad in themselves
Steroids	Check with your doctor, if you are on regular medication, whether any of the drugs you are taking regularly contain steroids. Few drugs are as effective at leaching away bones. Be warned, though, you may not be able to take the drugs that counteract this.
Diet	A good, healthy diet as a child can have an AMAZING effect upon keeping osteoporosis at bay. This is the most reliable way for the whole family to protect itself, as well as feeling so much better, too.

Risk Factor	What to look out for
Smoking	Smoking is known to depress hormone levels and suppress the activity of osteoblasts
Alcohol	Alcohol (in above moderate amounts) works in two ways. Firstly it suppresses the development of bone tissue - of importance to the younger student who likes to keep up with his rugby-playing mates in the SU bar! Also, for those of us who look backwards to being 40, alcohol can lead to very much grater risk of a fall & a fracture
Lethargy	Every time a bone is stressed, the osteoblasts are encouraged to lay down more material (hence tennis players having heavier racquet arms). The best time to put this exercise in is now. In children it can lead to strong bones, in adults it leads to healthier muscles and fewer falls.
Severe dieting	Minerals & vitamins must be taken in gradually over time. Long periods of poor supply cannot be compensated by high levels later on. Most diets are fine as long as they are balanced - ask your doctor or dietician if in doubt.

PROTECTING YOURSELF & YOUR WHOLE FAMILY

It is not really acceptable to single out one vulnerable member of the family when EVERY adult in the UK is at risk if we allow sloppy lifestyles and unbalanced modern diets. Consider introducing 1-3 of the following as a normal part of your household life:

1. **Healthy Diet:** The key is a healthy, balanced DAILY intake of vitamins and minerals. Calcium is present in most dairy products and vegetables. A pint of skimmed milk will give around 75% of your daily need. The Osteoporosis Society has a diet sheet available on their website (see end for details)
2. **Outdoor life:** moderate amounts of sunlight promote the formation of vitamin D₃. Deficiency can lead to rapid bone loss. Consider a diet that is rich in vitamin D₃, e.g. Fatty fish, cod-liver oil. Strong bones require BOTH forms of vitamin D
3. **Weight bearing exercise:** a **moderate** healthy exercise program, e.g. walking briskly for ½ hour per day, climbing several flights of stairs instead of using the lift. Avoid extreme exercise without medical advice as this can store up more worrying bone problems.
4. **Calcium Supplements:** these will not reverse osteoporosis but can be significant in its prevention and delay. There are literally hundreds available, many of which are of little value, check with your pharmacist. Note - these are NOT an alternative to a good diet. Absorption is increased in formulations that are acidified, e.g. contain betain hydrochloride. Calcium sources that simply reduce stomach acidity are next to useless.
5. **Testosterone:** Don't skip your injections or reduce your dose below the doctor's recommendation. Bone scans will give a good indication of dose rates. Remember an injection hurts a lot less than a broken bone, and a future of injections is more inviting that a future with severe osteoporosis.
6. **Drugs** prescribed by your doctor: A relatively new group of drugs, the Bisphosphonates are particularly effective at treating osteoporosis. Another drug, Calcitonin, is currently being investigated as a nasal spray.

TESTING FOR OSTEOPOROSIS

1. X-ray densitometry yielding a valuable t-score
2. Ultrasound densitometry - a newer alternative to x-ray
3. Biochemical urine tests - these are generally a lot of trouble, but a new test NTx promises to be extremely valuable and quick as well as giving a good indication of the aggression of the bone loss.
4. REGULAR checks are the only way to monitor bone density management and if performed every 6-12 months would give an excellent measure of the effectiveness of treatments.

FURTHER READING

Compston J (1998) *Understanding Osteoporosis* BMA Family Doctor Series (usually available in your local chemist shop/pharmacy) **Note: This is an excellent booklet and should be read by all families**

Webb M, Walker M, (2000), New insights into ageing bones, *Biologist*, 47 (1), Institute of Biology

Visit the [National Osteoporosis Society](http://www.nos.org.uk/) website at www.nos.org.uk/

NOTE:

The information contained in this paper should not be treated as specific advice to individuals. All such information should be checked with your Health Provider. Drug usage in particular is a matter for your Medical Practitioner.

About the KSA

The KSA has been supporting people in the UK with Klinefelter's Syndrome (KS), and their families and friends, since 1990. Our members are about as diverse as in any other support group; as well as those with Klinefelter's Syndrome themselves, we have parents, grandparents, wives, brothers, sisters, carers and friends.

Our aim is to assist everyone who comes into contact with KS. Of course, that goes beyond those who live with KS everyday, this could be a teacher searching for ways put together an action plan for a boy with KS, a doctor seeking to put a patient in contact with someone with more experience, or anyone else who needs to know more.

We support Adults (& their partners) as well as Children (& their families) who have Klinefelter's Syndrome (KS) and its variants. Our Members come from all over the UK and Ireland. We are both a source of information and a self-help Support Group. Members have the luxury of being able to meet others with similar experiences, to share what we have learned and then learn more together.