When does Osteoporosis start to matter? Bone health in Androgen Insensitivity Syndrome

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How do bones change as we get older?

The amount of bone in the body (bone mass) changes with age. Bone mass increases during childhood, increasing further during puberty to reach a maximum when people reach their early twenties. We start to lose bone mass from about the age of 40 years and then there is a steady decline thereafter. If bone mass becomes very low, fractures are more likely. This is why fractures are commoner in older people, because bones get weaker as we become older.

The hormones oestrogen and testosterone are important for maintaining normal bone mass, and males and females make both hormones. Oestrogen has the main effect on increasing and maintaining bone mass in both males and females. Its effects on bone start with the onset of puberty and continue into adulthood. Testosterone also increases bone mass but to a much lesser degree.

What is osteoporosis?

The word “osteoporosis” has a different meaning in adults and in children. In adults it describes people with very low bone mass who will have an increased tendency to fracture.

In children and teenagers, osteoporosis describes individuals who have low bone mass and also fracture easily. Therefore, to label a child as having osteoporosis, they must already fracture easily, whereas in adults it simply describes very low bone mass but fractures may not have occurred. The reason for this difference is because in children the strength of bones is not just related to bone mass but also to other factors like bone size. In adults, however, we have good evidence that fractures are strongly related to the amount of bone mass and we can therefore make a prediction of the likelihood to fracture based on a bone mass measurement.

Osteopenia is a word used to describe low bone mass or low bone density but not as low as that seen in osteoporosis.
How is bone mass measured?
To measure bone mass in children and adults a DXA (dual-energy x-ray absorptiometry) scan is used. This takes about 20 minutes and the measurement is compared to a reference range. A DXA scan gives a measurement of bone density and from this we infer the bone mass, although these are not strictly the same.

In children the measurements need to be adjusted for the size of the child otherwise shorter children will appear to have low bone density when in fact it was normal. This is less of a problem in adults who have completed growth. As we begin to understand more about bones other scanners may become available, but currently DXA scanners are routinely used across the UK.

Has bone density been studied in people with AIS?
Yes, there have been a number of studies published and mainly undertaken in adults. As AIS is rare the numbers of individuals included in each study was low. This means we have to be cautious about interpreting the results, generalising their meaning and need to keep an open mind as new evidence becomes available.

Do fractures occur more frequently in people with AIS?
Currently there are no studies that have shown an increased fracture incidence in children and adults with AIS.

Is bone density normal in AIS?
Several studies have shown that bone density tends to be lower than expected in adults with AIS. As bone density may be slightly low, it is possible that in the future this low level may increase the likelihood of osteoporosis.

Does HRT have a good effect on bone density in AIS?
Yes, people with AIS taking HRT have a higher bone density than those not taking HRT. The oestrogen treatment was shown to increase bone density.

Should androgens be taken to improve bone density?
No, currently there is no evidence to suggest this should be done.
Does the timing of gonadectomy affect bone density?
The studies available suggest that bone density is slightly higher in people with AIS receiving HRT following gonadectomy compared to those not taking HRT with gonads in place. However, there are very few studies that have been undertaken to answer this question definitively. Furthermore, other factors need to be taken into account regarding the timing of gonad removal.

What else can be done to optimise bone health?
A healthy lifestyle is very important during childhood and adulthood. Keeping fit is helpful as exercise stimulates new bone formation and increases bone density. A healthy diet is also essential as diets with plenty of calcium and vitamin D e.g. from dairy products, have been shown to increase and maintain bone density.

If you have concerns about your bones because of persistent bone pain or you have fractured a bone with minimal force it would be worth seeing your GP and a bone density scan may be requested. If your doctor has concerns about osteoporosis there are specific treatments (bisphosphonates) that may be offered to increase bone density. It would not be expected these would be used in children but in older people they are often used. Bisphosphonates are usually given as tablets under the supervision of your doctor.