



Winnipeg Regional
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À l'écoute de notre santé

Osteoporosis in Children

*A Family and
Caregiver Guide*



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Developed by Nicole Kirouac, RN, BN
in collaboration with the Pediatric Bone Health Project Team and The Children's Hospital Patient Education Committee

This booklet has been developed by Nicole Kirouac, RN, BN who is the Pediatric Endocrine Nurse Clinician and Bone Health Project Clinical Research Nurse at the Children's Hospital, HSC Winnipeg. Nicole has worked in collaboration with the Interdisciplinary Pediatric Bone Health Project Team and The Children's Hospital Patient Education Committee for the development and completion of this booklet. The information is for parents and caregivers of children with osteoporosis. The advice provided is general and not designed for a specific child. It is not meant to replace medical care. Please consult your child's doctor or therapist for specific advice.

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Contents

Osteoporosis is Real: No Bones About It!	4
What are Bones?	4
Osteoporosis	4
Nutrition	6
How much Calcium?	6
How much Vitamin D?.....	7
Activity	8
What is the right amount and type of exercise for your child?	8
Handle with Care	10
Parents Can Make a Difference	11
Role modeling healthy eating:.....	11
Role modeling healthy activity:.....	11
Safe play for preventing injuries:.....	12
Watching for fractures (broken bones)	12
Educating Others	13
Who Needs to Know?	14
What about Us?.....	15
What about Just Being a Kid?.....	15
What Do These Words Mean?.....	16
Other Sources of Information.....	17

Osteoporosis is Real: No Bones About It!

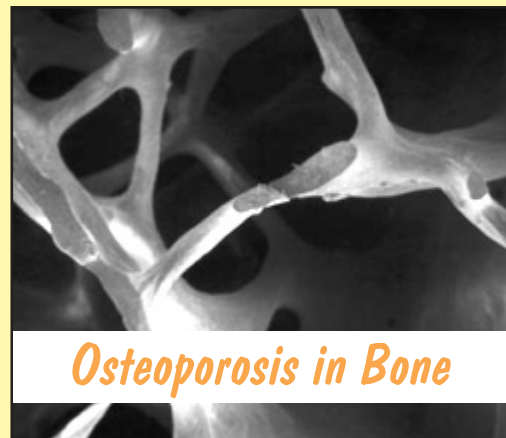
What are Bones?

- Bones are alive. Bones are always renewing themselves so that 10 to 30% of our bones are replaced each year! The old bone is removed and replaced by new bone. This renewal process is called “remodeling” – like when you remodel your house – out with the old and in with the new!
- Bones have cells in them just like the rest of the living parts in our bodies. The bone cells that take away old bone are called “Osteoclasts”, and the ones that build and harden new bones and called “Osteoblasts”. Think of blasting off into space! Your body can take off too with healthy strong bones. Osteoblasts need calcium, vitamin D and other bone building nutrients to help the bone harden. This keeps bones strong to hold us up so we can walk, run, jump and play.
- Childhood is the time when bone strength is built. Teenage years are the most important because more bone is being made than taken away. This means the osteoblasts are working way harder than the osteoclasts and that what we do as children and teens impacts the future of our bone health.

Osteoporosis

Osteoporosis (sounds like “os-tee-oh-puh-roh-sis”) is the word we use when bones are not as strong as they should be. The word “osteoporosis” comes from the term “porous bones.” When you have osteoporosis, your bones become weak and brittle. These porous bones can be so brittle or fragile that even a mild bang or an action like bending over can cause a break or fracture. A major cause of this weakness in the bones is a lack of calcium, vitamin D and other bone building nutrients. Other causes of weakness are: not enough exercise to build bones, medications that don’t let the osteoblasts work well and some sicknesses or diseases that speed up bone loss or prevent healthy bone growth.

THE INSIDE OF OUR BONES LOOKS LIKE THIS:



We used to think osteoporosis was a condition for old people but now we know differently. Kids' bones are always growing yet they can have problems just like adults including weak and brittle bones. With new ways of seeing bones by x-ray and something called DEXA scans (Dual Energy X-ray Absorptiometry, see page 16 for a description) as well as blood tests that show important bone building content, we now know that children suffer with this condition just like adults. Some children have even had broken bones from osteoporosis without knowing they had the condition.

You are reading this today because an important child you care for has, or is at real risk for, osteoporosis. Factors that put children at risk could be one or many listed here:

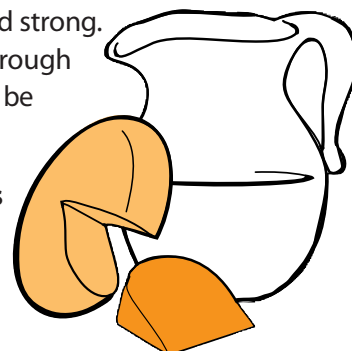
- A delay in the development of motor skills, for example not sitting by nine months of age or walking by eighteen months of age
- Children older than two years who have conditions that limit their ability to move around and have not been able to walk for more than three months
- Cerebral Palsy
- Osteogenesis Imperfecta
- Has had broken bones as a result of:
 - a fall from standing height or less (not a major fall)
 - daily care or activities (dressing, moving arms or legs for exercise)
- Broken bones in the back (compression fractures)
- Girls who have stopped having their periods after one year from their first period
- Cancer/Leukemia
- Cystic Fibrosis
- Muscular Dystrophy or other neuromuscular conditions
- Transplanted organs/tissues
- Chronic kidney disease
- Anorexia Nervosa (eating disorders)
- Seizure medications
- Vitamin D deficiency
- Not enough calcium intake
- Steroid treatment for three months or more (Prednisone, Pediapred, Dexamethasone for example)

The good news is that more has been learned about osteoporosis in children over the years with information on what may help build their bones and prevent fractures.

Nutrition

The foods we eat are very important in building and keeping bones healthy and strong. As children grow and get older they need to build strong bones to get them through their adult years. The mineral **calcium** is very important for bones and teeth to be strong. Most of the bone strength is built by the time a child is 18 years of age.

We get calcium from foods we eat and drink. **Calcium can't get into the bones without the help of a very important vitamin – that's Vitamin D!** You can have your child eat and drink foods with lots of calcium every day and it won't all get into their bones without the help of vitamin D.



How much Calcium?

The amount of calcium needed depends on your child's age. Because of their high risk for osteoporosis it is recommended they take in the following amounts of "elemental" calcium in their diet or through supplements (pills):

Age	Milligrams (mg) of elemental Calcium
1-3 Years	500 mg
4-8 Years	800 mg
9-18 Years	1300 mg

Source: DRI's, NAS, 2006

Foods containing Calcium:

Food	Food Portion	Elemental Calcium (mg) <i>approximately</i>
Canned sardines in oil with bones	100 g	400
Milk, evaporated	125 ml (1/2 cup)	340
Cheese, natural and processed	50 g	350
Milk (Whole, 2%, 1%, Skim, Chocolate, Buttermilk)	250 ml (1 cup)	300
Calcium fortified beverages (soy, rice, orange etc.)	250 ml (1 cup)	300 (check the label)
Tofu made with calcium	80 grams (1/3 cup)	280 (check the label)
Yogurt	125 g	225
Canned salmon with bones	75 g	200
Broccoli	250 ml (1 cup)	100
Cottage cheese, creamed cheese	125 ml (1/2 cup)	75
Processed cheese spread	2 tablespoons	170
Dried figs	60 ml (1/4 cup)	60

Tips for Calcium Intake:

- A daily multi-vitamin does not contain enough calcium to be adequate as a supplement.
- All calcium supplements should be taken with food or soon after eating. They are absorbed more effectively when there is food in the stomach.

Some tablets are very large and may be difficult to swallow. In this case, try chewable or effervescent (melting) tablets or a liquid form.

- Avoid supplements that have calcium from “oyster shells”, “dolomite”, and “bone meal”. They are not recommended, as these sources can contain variable amounts of lead. **Lead in a child’s body can have negative effects on development.**
- Calcium supplements will decrease the absorption of iron supplements and should be timed away from these.



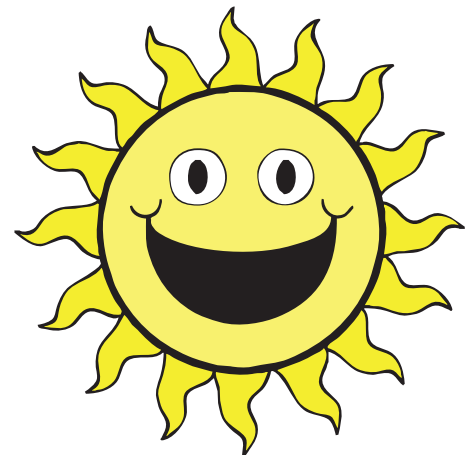
**Reference: Compendium of Pharmaceuticals and Specialties, The Canadian Drug Reference for Health Professionals. Canadian Pharmacists Association, 2008*

How much Vitamin D?

The sun gives us vitamin D through our skin, especially in the summer months. With the risk of cancer from the UV rays of the sun it is important to use sunscreen, hats and sunglasses. This means that vitamin D from the sun will never be able to help us enough. Instead, because of your child’s increased risk for osteoporosis they need to take some vitamin D by mouth.

The type of vitamin D taken by mouth determines how it is absorbed in the body and how well it works. “Cholecalciferol” is the preferred supplement for all children. Use D drops, D-Vi-Sol, Pediavit D or D3 generics. Check the labels to know exactly how many IU (International Units) there are in every drop, milliliter or tablet or ask your pharmacist for help. Because of your child’s high risk for osteoporosis we recommend they take in at least the following amounts of vitamin D per day.

Age	International Units per Day of Vitamin D3 (Cholecalciferol)
12 years and younger	1000 IU
Greater than 12 years	2000 IU



We are recommending the above vitamin D supplements before doing the blood test for vitamin D called Vit D25(OH) because of your child’s risk for osteoporosis and fractures. After at least one month on the above vitamin D supplements we need to make sure that your child’s Vit D25(OH) level is at its best “winter” level of over 75 nmol/L. Your doctor may increase the dose of vitamin D to ensure a normal Vit D25(OH) level.

Activity

Just like muscles, bones get stronger when you move and use them. Not enough exercise will make your muscles and bones weak and will limit the things you can do. Too much exercise may make you sore and tired.

What is the right amount and type of exercise for your child?

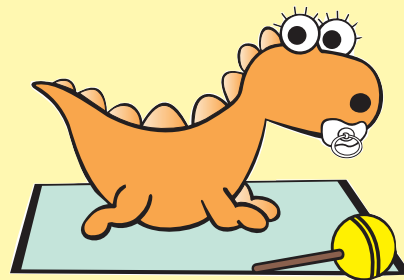
IT DEPENDS !!!:

- On your child's general health and age.
Always check with your doctor if you are concerned that your child's medical condition may limit the activity they can safely do.
- On what they are used to doing right now:
 - How fit they are.
 - If they are not used to exercising regularly, they will have to gradually get used to activity.
- On what they would like to do. We all find that we enjoy some activities more than others and will be more willing to exercise if we like what we are doing.

FOR BABIES:

Even very young babies can benefit from being allowed to play in different positions. Although babies need to be placed on their backs to sleep, when they are awake and supervised they further develop the muscles and bones in their body by lying on their sides, on their tummies and being held in sitting positions for play time. Many brief play sessions throughout the day as part of baby's daily routine can help overall development. For example, try a few minutes of tummy time after a diaper change. Babies also benefit from some supervised play time on the floor (on a blanket or mat) as they will learn to move and explore.

If your baby has a medical condition, check with your doctor to make sure there are no restrictions to play or positions.



FOR CHILDREN (walking age and older):

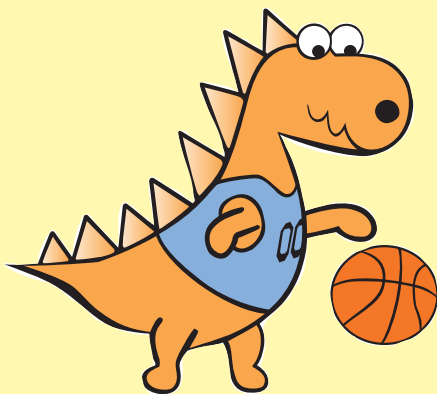
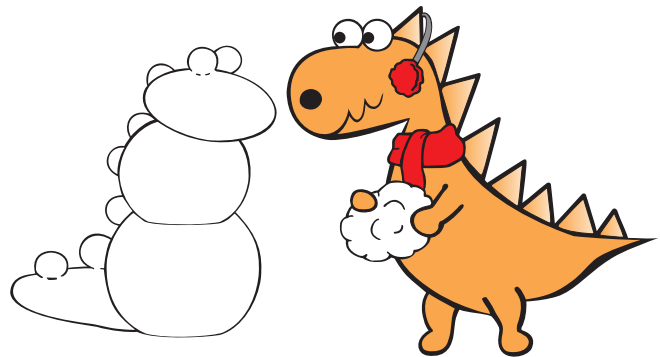
There are different types of exercise:

- 1) **Non-impact** – e.g. Tai Chi, yoga, stretching, swimming and bicycling. These can be done daily.
- 2) **Strengthening exercises** – working with weights, resistance bands or using body weight as a resistance e.g. push-ups, sit-ups. For younger children, e.g. “crab” walking, “bear” walking or building a snowman. These can be done 2 or 3 times a week.
- 3) **Low impact weight bearing exercises** like walking, using a treadmill or stair stepper, low impact aerobics, snowshoeing, or just walking in snow or sand. These can be done daily.
- 4) **High impact weight bearing exercises** like jogging, skipping rope, dancing, tennis, basketball. These can be done 4 or 5 times a week.



A physiotherapist can help you plan a healthy and safe activity program to suit you.

A physiotherapist can also give you more ideas about how to handle and play with your child to promote healthy bones and muscles.

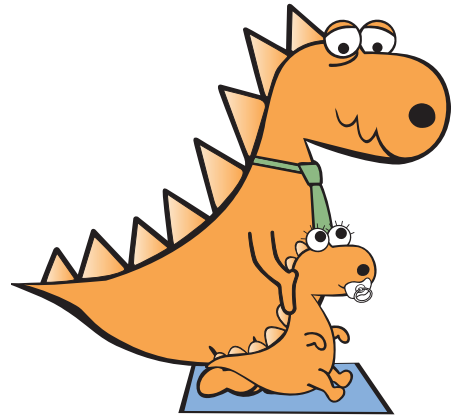


The high impact weight bearing exercises provide the most benefit for building stronger bones but may not be a good starting point if your child is not normally active or has been ill. Starting with non-impact activities may be safer and healthier for the child who has not been very active. Aerobic exercises done for at least 20 minutes (as in #3 and #4) can also help make one's heart and lungs work better.

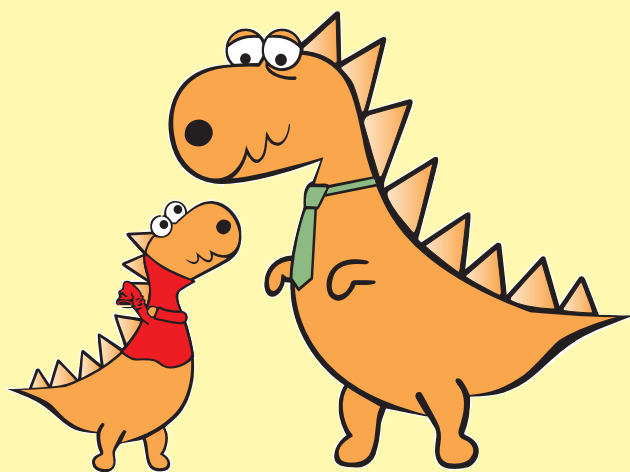
Handle with Care

Whether you are trying to dress, bathe, or even just cuddle your child, here are a few simple guidelines to help make sure that they are not accidentally injured while you are moving them around and positioning them:

- Maximize the surface area touching the child:
 - Use your whole hand instead of just a finger or two.
 - Use the pads of the fingers instead of the tips of the fingers.
- Always use smooth, slow movements.
- Never force, pull or yank on an arm or leg or try to move it further than it wants to go.
- Try to make sure that the child is well supported when doing activities that need them to be sitting up:
 - Head and trunk support if needed.
 - Hips, knees and ankles bent in 90 degrees flexion if possible.
- Always get the child to help as much as possible. The risk of injury is minimized with active participation.
- Try clothes that have buttons or snaps in the front to minimize the risk of injury during dressing activities.
- When dressing a child who cannot dress themselves, gently bring the clothes over the child's arm/leg being careful not to pull on or twist the arm/leg.



Every child is different. This means there is not only one way to care for children with osteoporosis to help reduce the risk of injury. If you are having trouble moving or positioning your child, an Occupational Therapist can work with you to come up with specific ways to help make things easier.



There is a video and handout available from the Children's Hospital Occupational and Physiotherapy departments for parents and others caring for children with different muscle tone as well as those children at high risk for fractures because of osteoporosis. This video gives examples of safe handling procedures for daily care and play. Please ask your health care provider for access to this video.

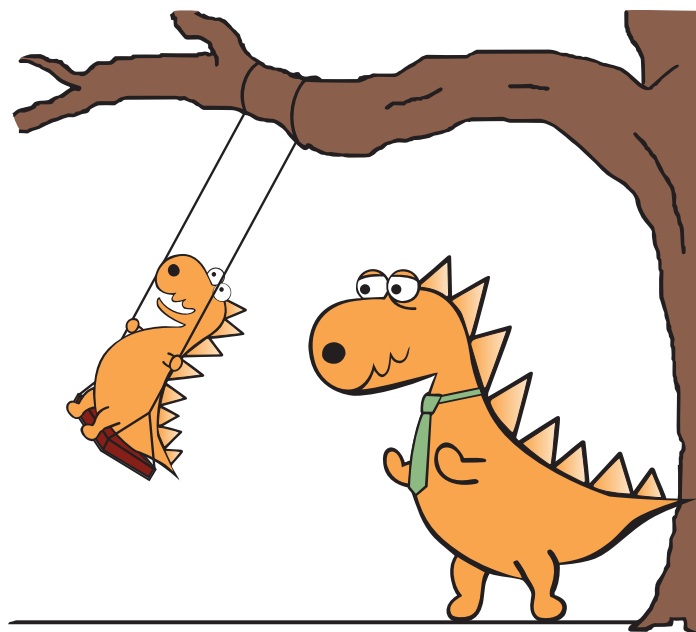
Parents Can Make a Difference

Role modeling healthy eating:

- Make healthy eating a family commitment.
- Plan meals in advance and shop together to have input from the children.
- Include food from all four food groups – pay attention to calcium content!
- Encourage age appropriate portion sizes.
- Eat together at the table with distractions off (e.g.: TV, computer, video games)
- Continue to introduce foods that your child did not like in the past as they may like them now!
- See Canada’s Food Guide, available in over ten languages for further healthy eating and food ideas. The link is listed on page 17 of this booklet, or you can ask your health care provider for a copy.

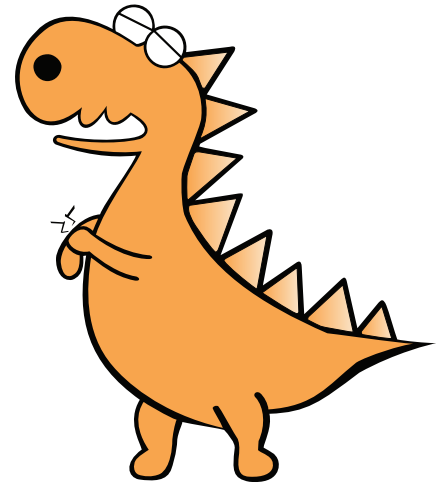
Role modeling healthy activity:

- Play with your children as much as you can.
- Make the home/yard your “gym”. Let them see you exercise and they will want to join you.
- Be an example to your children and use the right equipment for the activity (e.g.: helmet and proper shoes).
- Choose to walk when possible and take stairs instead of elevators. (We understand that if your child cannot walk this is not possible).
- Find some activity that the family can do together that is safe for your child and encourage all family members to join in the fun.
- See Canada’s Physical Activity Guide for further recommendations for healthy active lifestyles for children of different ages and stages. The link is listed on page 17 of this booklet or you can ask your health care provider.



Safe play for preventing injuries:

- Make sure your child wears a helmet and knee/elbow pads for sports like bike riding and roller blading.
- Make sure your child has the right shoes for their activities. Good fitting shoes that support the ankles, soles and prevent tripping/slipping.
- Ask your health care team if it is safe for your child to play contact sports. Injuries are very hard to prevent in contact sports with lots of players and balls or sports equipment like sticks coming from different directions.

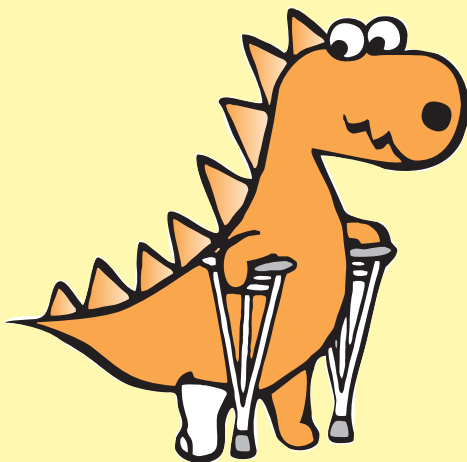


Watching for fractures (broken bones)

Fractures or broken bones may still happen even if you are taking care to play safe. Children may break bones from an accident involving force or trauma like falling off a bike or off a play structure. These can happen to any child or adult. In the case of fragile bones and fractures that happen without an obvious cause, this is likely due to osteoporosis or weak brittle bones.

Things to watch for in your child:

1. Complaint of pain in a bone that gets worse with movement.
2. Swelling or bruising over a bone.
3. Deformed limb (arm, leg, hand or foot).
4. Child is not using the limb – they are “guarding” it from harm.
5. Child winces or looks like they may be uncomfortable during routine play or exercises.

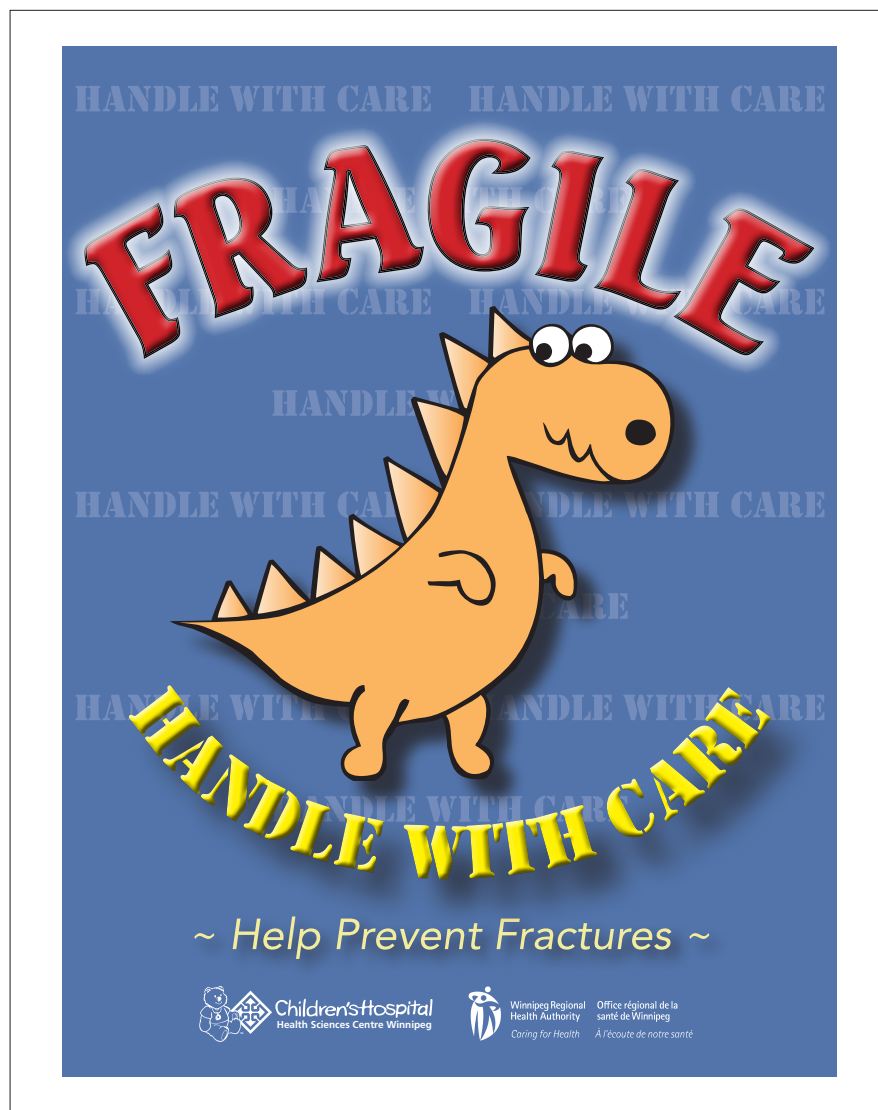


If your child has any of these symptoms that are new you are advised to take them to their doctor or the closest Emergency Room for assessment and ensure that you let the health professionals know of your child's risk for osteoporosis and fractures.

Educating Others

We want to make sure that anyone helping to care for your child knows that they need to be very careful when caring for them to prevent broken bones. This poster/sticker will be used in hospital, and a sticker format of it found on the next page is available for home and in the community to let people know. The dinosaur mascot is an "Osteosaurus" and his nickname is "Ostey". He can go with your child as he/she goes through his/her daily routine and help raise awareness, to protect him/her from getting broken bones that can happen during regular daily care and play.

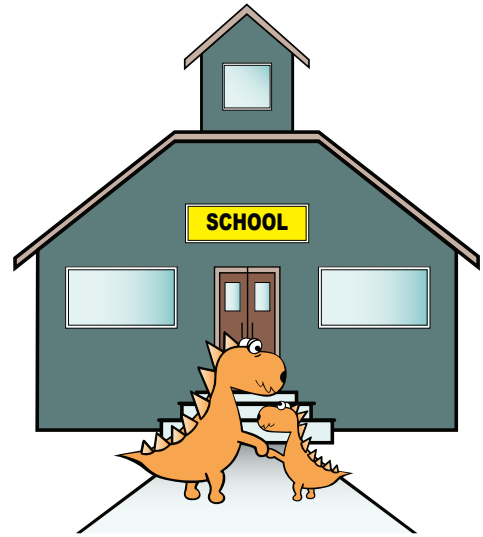
Hi Kids! I'm Ostey. I will be there with you to try and keep you safe throughout your day!



Who Needs to Know?

The following is a list of people you should consider talking to and sharing this handbook with to keep your child as safe as possible and prevent fractures:

- Daycare and school staff:
 - Teachers
 - Teaching assistants
 - Recess supervisors: to make sure your child is in safe play activities
 - Gym teachers and coaches: so they understand why your child cannot participate in contact sports but they can still include them in every way possible. Some examples are by scorekeeping, assistant coaching and letting them understand the game
- Babysitters: they need the right information to ensure safe play and personal care activities
- Child's friends and playmates: so they can help by watching for hazards and ensure they are not too rough with your child
- Parents of your child's close friends especially where your child will play or visit
- Your family and good friends need to know so they can help provide emotional support for your child and you as a parent **as well as** help keep your child safe while having fun



Put "Ostey" to work!

Ask your health care provider for signage for wheelchair/stroller and classroom if your child is dependent on others for daily care.

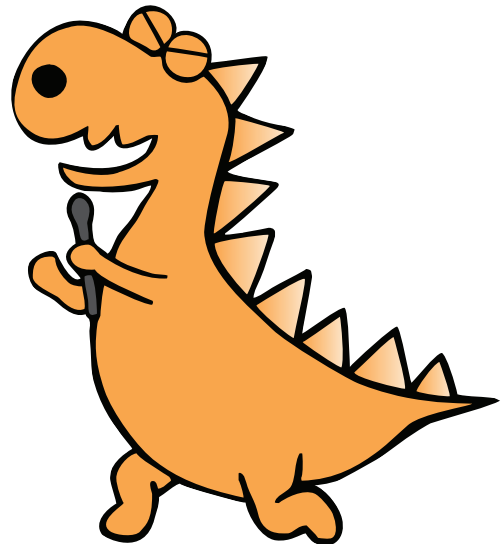
What About Us?

Caregivers can feel “stressed” when raising a child with different needs who requires special care and attention. Please know that you do not need to travel this road alone. There are others you can share with and learn from. Ask your health care provider about who you can talk to regarding how you are handling the daily activities and stress that this life can bring. You are providing a wonderful, safe place for your child to grow and live. Remember that taking care of yourself is just as important as taking care of your child. Ask for help, and ask again if you need to. There are resources available. Your health care team can help you find the one that fits your family’s needs at this time.

What About Just Being a Kid?

We know that it can be hard for a child if they feel that they have to limit their activities because of having fragile bones. We encourage you to take a look at the following list of ways to help your child participate and just be a kid!

- Emphasize their strengths: what they **CAN** do versus what they cannot.
- Make foods fun: prepare foods in different ways to encourage your child to try new things and give them choices when you can.
- Offer them safe alternative ways to take part in activities and allow them to be a part of the team. For example: Helping coaches for sports, score-keeping, cheering on the team and even coordinating “cheers”. This keeps them with their friends!
- Focus on activities they **CAN** do such as:
 - Walking.
 - Wheelchair activities, if appropriate.
 - Swimming. This may not be “bone building” but it is lots of fun!
 - Riding bikes- don’t forget the helmet and pads.
 - Non-contact sports like tennis or badminton and shooting hoops with a friend.
 - Drama.
 - Crafts.
 - Singing.
 - Cooking.
 - Telling jokes.



What Do These Words Mean?

- Calcium** – A mineral needed for building strong bones. This is found in most dairy products and fortified foods. Calcium can also be taken by tablet or chewable supplement.
- Cholecalciferol** – A form of vitamin D3 that comes from the sun or can be taken by mouth through a supplement.
- DEXA Scan** – Dual energy x-ray absorptiometry. This is a test to detect low bone density and help diagnose osteoporosis. This test can be done on the spine, hip, forearm, heel or total body and does require holding still. It is a form of x-ray using a special machine at an x-ray department.
- Effervescent** - dissolves in water quickly, causes a fizzing or bubbling reaction. Describes how some calcium tablets are made to dissolve in water.
- Fortified** – Something that has been added into the original food. For example calcium is added into certain foods or drinks and they are then called “fortified”.
- Osteoblasts** – The bone cells that build and harden new bones.
- Osteoclasts** - The bone cells that take away old bone.
- Osteoporosis** - A condition in which the bones become so porous and weak that they are likely to break from a low-impact injury or exercise.
- Osteosaurus** – A new dinosaur named especially for children at risk for or with osteoporosis to teach them and help others know they are fragile.
- Supplement** – Something extra that needs to be taken.
- Vitamin D** – A vitamin that is made by the body after it is exposed to sunlight. It helps the body use calcium to keep bones strong. It is found in a few foods such as fortified milk, cereal and fatty fish.

Other Sources of Information

Best Bones for Life website for teenage girls (American)

www.bestbonesforever.gov

Canada's Food Guide (available in 10 different languages)

<http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php>

Canada's Physical Activity Guide

<http://www.phac-aspc.gc.ca/hp-ps/hl-mvs/pag-gap/cy-ej/index-eng.php>

Dietitians of Canada

www.dietitians.ca

Manitoba Milk Producers

www.milk.mb.ca

488-6455

National Institutes of Arthritis and Musculoskeletal and Skin Diseases and the NIH Osteoporosis and Related Bone Diseases – National Resource Centre

<http://catalog.niams.nih.gov>

National Osteoporosis Foundation

www.nof.org

Osteogenesis Imperfecta Foundation

www.oif.org

Osteoporosis Society of Canada

www.osteoporosis.ca

1-800-463-6842

Osteoporosis Society of Canada Manitoba Chapter

(204) 772-3498

Email: Manitoba@osteoporosis.ca

Notes



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Index # 120.08.01