Bone Metastases

Helping You to Help Yourself

A guide for patients diagnosed with Bone Metastases

Sunnybrook Odette Cancer Centre

A Cancer Care Ontario Partner
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It is up-to-date and represents current practices in Canada. The Odette Cancer Centre has made every effort to ensure that information included within this program is accurate.

It is intended to meet the information needs of patients, caregivers and health professionals. It is not intended to replace medical information or advice offered by your physician. The information included cannot substitute for self-diagnosis or medical advice and makes no guarantees, nor can it assume any legal liability for the accuracy, completeness, or usefulness of such information or for any damage incurred directly or indirectly from the information. Reference to any specific product does not imply its endorsement, recommendation or favouring by the Odette Cancer Centre. Questions or concerns should be addressed with members of your cancer health care team.

Editor-In-Chief: Ms. Philiz Goh, BSc Hons Kin, C.K., BScN(C)

Editors: Dr. Margaret Fitch, BN, MSc, PhD
Dr. Edward Chow, MBBS, PhD, FRCPC

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A special thank you to all the patients who read and gave their input to help improve this book.

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Second Edition
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Dear Patient and Family,

The purpose of this book is to provide you and your family with the means of understanding how to cope and live with this diagnosis.

This book contains information based on research and patient input. Patients have helped to improve this book to meet your information needs.

This book has information specific to bone metastases. You may not need to use all of it at this time. We hope you will keep the book as a reference for future use.

We recommend that you discuss this book with your nurse before taking it home. Your nurse will be able to help explain how best to use the information and materials contained in this book and help answer any questions or concerns you may have.

The Bone Metastases Site Group and the Department of Nursing at the Odette Cancer Centre have worked together to develop this book to help you help yourself. This bone metastases book is generously supported by an education grant from Novartis Oncology.
What are Bone Metastases?

Bone Metastases (meh-TAS-tuh-seas) happen when cancer cells from your first cancer (primary cancer site) break away from the tumour and travel through the blood stream to the bones. Once these cells settle into the bone(s), they grow and form new tumours.

Cancer that has spread to the bones can damage the bones in two ways:

1. It can create small holes, which cause the bones to be weak and fragile.
2. It can cause bone to grow abnormally, which can make the bone unstable and fragile.

Bone metastases can involve any bone. Most commonly they spread to the spine, ribs, pelvis, arms, legs and skull. **Primary cancer that has spread to the bones is not the same as a primary bone cancer that started in the bone.**

How common are Bone Metastases?

Bone metastases are a frequent complication of cancer. The most common cancers that spread to the bone start in the breast and prostate. Lung, kidney (renal) and thyroid cancers, as well as multiple myeloma can also involve the bone. When cancer has spread to the bone(s), it is still named after the part of body where it started. For example, if breast cancer spreads to the bone, it is called breast cancer with bone metastases. Sometimes bone metastases may have already
occurred when a patient is first diagnosed with cancer or may be discovered before the primary tumour is found.

What are the symptoms?

Common symptoms of bone metastases are

- Pain (see page 41)
- Loss of the ability to maintain usual activities and lifestyle
- Bone(s) may break
- High calcium levels in the blood stream ("Hypercalcemia")

What complications should I look out for?

Complications may happen when someone has bone metastases. The information below is to help you be aware of conditions that you need to tell your cancer health care team about. Not all patients will experience these complications. IF you do suspect that you may be experiencing one of these complications, please call your doctor or nurse immediately.

Hypercalcemia

Hypercalcemia (hi-per-kal-see-me-uh) occurs when the calcium level in your bloodstream is higher than normal. This can be caused by bone metastases that weaken and destroy the bone resulting in the release of calcium into your blood.

Hypercalcemia can occur with any type of cancer. It is most often found in multiple myeloma, breast and lung cancers.
Symptoms of Hypercalcemia:

- Loss of appetite
- Feeling sick to your stomach
- Thirst
- Constipation
- Confusion
- Fatigue
- Weak muscles
- Need to pass urine often
- Increased bone pain

Untreated hypercalcemia can be dangerous, but often can be treated successfully. You need to tell a member of your cancer health care team if you have these symptoms.

A common goal in treating hypercalcemia is to make sure there are enough fluids in your body. Your doctor may ask you to drink more fluids. You may also need to have fluids through a vein in your arm. For example, Pamidronate (Aredia®, Pamidronate Injection®) is a drug commonly used to treat hypercalcemia and is given through a vein in your arm (see page 36).

Every patient is unique and therefore treatments may be different.

**Bone Fractures**

Cancer that has spread to the bone may cause bones to weaken and therefore be at risk for breaking or fracturing. Breaks in the bones may happen without warning and can be difficult to prevent.
Symptoms of Fractures:

- Sharp, sudden pain in one spot
- Pain may quickly become severe
- Pain may worsen with movement
- Swelling, warmth, bruising
- Hard to walk or stand

Weight-bearing bones (thigh bone or femur; lower leg bone or tibia) and larger sized tumours are at higher risk of breaking than other bones with metastases. Symptoms of high risk bone metastases ("impending fracture") of the long bones:

- Consistent increased pain in your hip, thigh or leg
- The pain gets worse when you stand or walk

If you have severe pain with movement, please call your doctor or nurse and go to the nearest hospital emergency department to have an X-ray done. This will tell if you have broken your bone.

Depending on your condition, you may need surgery or radiation therapy or both for treatment. Pain medication will be adjusted for your comfort and you may need a sling, a splint, a cast or have a walking aid to provide support to the affected area. You may also need to see a physiotherapist (PT) or an occupational therapist (OT) (See page 78 and 75) to help with rehabilitation following your fracture and prevention of future fractures. Please talk with your doctor if you would like to meet with either of these professionals.

Note that every patient is unique and therefore treatments may vary.
Prevention:

Here are some suggestions to help you prevent falls and fractures at home:

- Remove throw rugs
- Keep hallways clear of clutter
- Wear non-slip footwear
- Avoid walking on uneven surfaces
- Use a cane or walker for support
- Use railings on stairs
- Roll over gently in bed
- Be careful when going in and out of a vehicle

Spinal Cord Compression (SCC)

What is the spine?

The medical name for the bones of the back is the “spinal column” or “spine”. The spine starts just below the skull and goes down the neck, upper back, and lower back to the tailbone. The spine is a collection of bones that is very much like a stack of building blocks called the "vertebrae" or "vertebral" bodies.

Cancer that has spread to the bones in the spine may lead to spinal cord compression. **SCC is a medical emergency** caused by tumour pressing on the spinal cord. This can result in pain as well as sudden loss of feeling and function in arms, legs, bowel or bladder. This can occur over 24-48 hours and needs to be diagnosed and treated immediately to prevent permanent damage. **You need to get medical help right away.**
Any patient with cancer that has spread to the bones of the spine (vertebrae) is at risk for spinal cord compression. Patients with multiple myeloma or cancers of the breast, prostate, lung or kidney are at the highest risk.

Symptoms of Spinal Cord Compression:

- Rapid increase in back pain that keeps getting worse
- Difficulty walking or loss of balance
- Weakness, heaviness or stiffness in arms or legs
- Numbness and tingling in arms or legs, hands or feet
- Inability to hold urine or bowel movements; or inability to pass urine or bowel movements

If you experience any of these symptoms, please call your doctor or nurse and go to the nearest hospital emergency department immediately. Tell them you are worried about “Spinal Cord Compression.”

By looking for urgent medical treatment, you will have the best chance of avoiding problems such as paralysis. Have a family member go with you and take with you all your medications.

An MRI is usually done to confirm if a SCC is happening (see page 22). Based on the results of the MRI, your course of treatment will be decided. Possible treatments include radiation therapy (see page 26), medications to control pain and swelling (see page 41) and sometimes surgery. The goals of these treatments are to avoid any loss of function, help improve the function of your arms and legs, to improve pain, and to keep your spine stable.

Every patient is unique and therefore treatments may be different.
How do we measure symptoms?

ESAS (Edmonton Symptom Assessment System)

Many cancer centres use the ESAS tool to see if patients are experiencing cancer related symptoms. The ESAS allows doctors and nurses to focus on the symptoms causing the greatest distress, and also helps to monitor changes in a patient's symptoms that occur over time. An example of the ESAS can be found on the next page.
Edmonton Symptom Assessment System (ESAS)

Date of Completion: __________ Time: __________

Please circle the number that best describes:

No pain

Worst possible pain

Not tired

Worst possible tiredness

Not nauseated

Worst possible nausea

Not depressed

Worst possible depression

Not anxious

Worst possible anxiety

Not drowsy

Worst possible drowsiness

Best appetite

Worst possible appetite

Best feeling of well being

Worst possible feeling of well being

No shortness of breath

Worst possible shortness of breath

Other problem

ESAS completed by:
- Patient
- Health professional
- Family
- Assisted by family or health professional
Maintaining quality of life is an important goal for patients with bone metastases. Several quality of life questionnaires have been developed. You may be asked to complete one or more of these questionnaires when you see your health care team.

The Bone Metastases module (BM22) quality of life questionnaire was developed to look at problems experienced by patients with bone metastases.

The BM22 helps your health care team to determine what issues are the most concerning for you. You and your health care team can decide on a plan of care to improve the problems you are experiencing. Identifying the most concerning issues is the first step improving your quality of life. An example of the Bone Metastases module (BM22) quality of life questionnaire is found in Appendix I.
This section will give a brief overview on the different types of tests that may help your cancer health care team diagnose and monitor your condition. Please note that not all patients will need all of the various tests listed below.

**X-Rays**

X-rays can tell your doctor where on your skeleton the cancer has spread. They can also provide general information about the size and shape of the tumour(s). X-rays produce images of the skeleton and some internal organs by using special equipment that deliver a highly controlled amount of radiation (x-rays).

This image shows bone metastases in the lower leg.

A skeletal survey is a series of x-rays of most of the bones in the body (skull, entire spine, pelvis, ribs, both arms and thighs). This procedure is similar to the normal x-rays and there is no preparation required.
**Bone Scan**

A bone scan can detect the presence and extent of metastatic bone disease, as well as other bone abnormalities. There are no specific preparations needed. You may eat and drink as usual. There are two parts to this procedure.

**Part 1**: Takes about 15 minutes.

- You receive an injection of a small amount of a radioactive material into a vein in your arm (similar to having blood drawn).
- The radioactive material injected is specific for bone imaging.
- During the injection, using a camera, images may be taken of the radioactive material as it flows through your bloodstream.
- This procedure should not make you drowsy, ill, or result in any adverse reaction.

**Note: A Waiting Period of 3 hours is required.**

- After the injection, you may leave the department and return in 3 hours. This waiting period allows the radioactive material to be absorbed by the bones.
- During the 3 hour waiting period, you are encouraged to drink at least 1 liter of liquids (any kind). This allows us to image your bones more clearly.

**Part 2**: Requires 1 hour of imaging

- You will lie on an examination type table and will be instructed to remain still (see picture on next page).
• The camera is positioned above and below you and will move slowly from your head to your feet.
• You are advised to keep drinking fluids after this procedure to help clear the remaining radioactive material from your body.

The camera does not produce any radiation. It records the signal from the radioactive material you received earlier. The amount of radiation is no more than what you would receive from similar x-ray procedures. You can go back to all your normal activities after the scan.

The total time for this procedure and preparation is 4½ to 5 hours.
This image shows an example of a completed bone scan with bone metastases.

**Computed Tomography (CT) Scan**

A CT scan is a medical imaging method that obtains 3D images of body structures in "slices". Sometimes you may need to have an injection or a special drink to get better images of the organs or blood vessels. A CT scan can be used to detect cancer that has spread to other parts of the body, including the bone(s).

You will be in the middle of the tube during the examination (see image on next page). An average CT scan takes about 15-30 minutes. During the scan, you will need to lie still. If you have difficulty lying still due to pain, or you feel claustrophobic in confined spaces, speak to your physician before your CT appointment.
This shows a normal CT scan of the spinal canal

This shows a high risk spinal cord compression

This is a CT machine
Magnetic Resonance Imaging (MRI)

Magnetic Resonance Imaging (MRI) is a test that provides very detailed pictures of the body. It is very helpful when looking at spinal bones.

The MRI machine is tube-like in design; you will be in the middle of the tube for the scan. You will be given earplugs to help reduce the noise made by the machine. You will also be given a call bell to hold in case you need to speak with the technologist urgently.

To make sure the strong magnetic field will cause you no harm, you will be asked to fill out a screening form prior to your examination; you and a qualified health care professional should review these questions together. The purpose of the screening is to make sure that you do not have metal devices, or other implants that would be attracted to the magnet. A technologist will review the screening form again with you prior to your scan.

An MRI on average will take 30-60 minutes. During that time you will need to lie still. If you have difficulty lying still for long periods of time due to pain, or you feel claustrophobic in confined spaces, speak to your physician prior to your MRI appointment.
This is a MRI machine.

The image above shows an impending spinal cord compression.
**Biopsy**

Sometimes a biopsy needs to be done to confirm that you have bone metastases. Scans may only show an unusual change in the bone and a biopsy may be needed.

A needle biopsy removes a small sample of tumour from the affected area with the help of a CT scanner or ultrasound.

Please ask the doctor doing the biopsy or the nurse about your condition, the specific procedure and risks to make sure you are fully informed.
What treatments might I expect?

Your cancer health care team will discuss with you which of these treatments may be best in your situation.

**Radiation Therapy (Radiotherapy):**

Radiation Therapy is a high energy x-ray beam that acts to kill tumour cells. Radiation therapy x-rays are much higher energy than diagnostic x-rays.

"Palliative" radiation refers to short course radiation aimed at the relief of symptoms. Pain is improved in the majority of patients; about 70% of people with cancer in the bones will have some pain relief. Radiation can relieve pain within 2-4 weeks after treatment. Radiation may reduce the chance of further bone destruction and can help bone healing after a fracture.

What does Radiation Therapy involve?

After your appointment with the radiation oncologist, you will be sent for a planning (also called Simulation) session. The planning session allows the radiation therapists and your doctor to plan out the exact area that needs to be treated while you lie on the bed that looks just like a CT scanner. The delivery of the radiation treatment will be given once the treatment has been planned. You may have one treatment or many treatments. The treatment usually takes 15-30 minutes. Most of this time is spent getting you into the treatment position. The radiation machine is usually on for less than 5 minutes.
What possible side effects are there?

Side effects depend on the amount of radiation you are given and what area of the body is being treated.

1. Fatigue (tiredness, weakness) is a common side effect of radiotherapy treatment. Patients may feel more fatigued one or two weeks after the end of treatment compared to during treatment. It may take a few weeks to get back to normal. Information about how to cope with fatigue is on page 59.

2. Pain flare (an increase in pain in the treatment area during or shortly after radiation) occurs in some people. Pain flare is temporary and usually happens 24-48 hours after the first treatment. The flare may last for 1-5 days or longer after radiation treatment. It is often managed by pain medication. Please let any member of your treatment team know if you have any problems with your pain control. Information about pain medication is found on page 41.

3. Other examples of side effects:
   - Your skin may get red, become dry, or get flaky. Some patients may have little or no skin reaction.
   - You may lose hair in the area radiated. You will begin to notice hair loss 1-2 weeks after your radiation treatment is over. Hair will probably come back.
• You may feel some nausea or stomach upset if radiation is passing through the brain or abdomen. It may occur within 1 to 6 hours after your radiation. Sometimes patients are prescribed an anti-nausea (anti-emetic) medication to be taken before each radiation treatment.

• You may get some diarrhea if the radiation is passing through the abdomen or pelvis. If you develop more than two or three loose watery bowel movements per day, tell your health care provider.

Most side effects of your treatment are short-lived and can be managed by medication(s) given to you by your doctor.

**Can I receive Radiation Therapy again if I have pain in the same spot?**

You *may* have radiotherapy more than once in the same spot to help reduce your pain. Your doctor will discuss whether repeat radiotherapy is possible and what other treatment options you have (for example, further medications, surgery or chemotherapy).

**Stereotactic Body Radiosurgery (SBRS):**

SBRS means one to five treatments of radiation that is highly focused on the tumour. This involves both the radiation oncologist and surgeon. The aim of SBRS is to prevent the tumour from growing, to shrink the tumour, and to relieve the symptoms caused by the tumour (for example, pain).
Who is radiosurgery used for?

It can be used for certain patients with bone metastases in the spine as a way to provide more radiation to the specific area while sparing normal tissues from high doses of radiation. SBRS can also be used if you have had prior radiation to that area.

What does radiosurgery involve?

For the patients with metastases to the spine, this involves coming for a CT scan and being placed in a specialized body cushion designed to keep the spine in the same place each day. A few days later you come back for your first treatment. Each session lasts 30-45 minutes. Special imaging is used each day on the radiation machine to make sure the tumour is targeted accurately.

Hospitalization is not required. You can come and go from your home for treatment.

More detailed instructions will be provided by the physician or nurse involved with the procedure.

What possible side effects are there with Radiosurgery?

The pain may get slightly worse before getting better (pain flare), and you may need some pain medications. Other side effects depend on the area treated. If radiated near the head region, then you may get some pain when swallowing or discomfort in the throat or cough. If radiated in the lower back, you may get some nausea or stomach upset or loose bowels.
Generally SBRS is very well tolerated as it is a highly focused treatment.

**Surgery:**

Bone metastases may cause bones to weaken and be at risk for breaking. Surgery may be possible to fix broken bones or strengthen weakened bones to prevent this. Surgery provides support, reduces pain and improves movement. Radiotherapy may be required after surgery.

**What does surgery involve?**

Your doctor will discuss the options available.

**What possible side effects are there with Surgery?**

Since every patient’s condition is unique, the side effects will be different for each patient. Please ask your surgeon about specific side effects.
Percutaneous Vertebroplasty:

What is Percutaneous Vertebroplasty used for?

Percutaneous Vertebroplasty (PVP) is a treatment for vertebral compression fractures (VCFs), which are fractures of the back bones. Its main purpose is to treat the pain caused by VCFs and it is very effective in doing this. It also helps prevent the bone from breaking any more than it already has. Sometimes vertebroplasty is used to prevent a fracture from happening. Not all bone fractures are suitable for PVP.

What is a vertebral compression fracture?

When standing upright, the spinal column supports the weight of the body, which means that the vertebrae have a lot of pressure on them. If a vertebra is weakened for some reason, the weight of the body can cause it to crack. As more cracks develop, the bone starts to flatten out. When this happens, this is called a “vertebral compression fracture” or “VCF” for short. VCFs can be very painful. Most VCFs occur in the mid and upper back or lower back.

What does PVP involve?

PVP is done as an outpatient procedure, where VCFs are stabilized by injecting bone cement into the vertebrae involved with local freezing to numb the area. There is no cutting, the patient is not asleep but sedated, and it does not usually require an overnight hospital stay. People who have
vertebroplasty generally come to the hospital in the morning and leave for home in the afternoon.

More detailed instructions will be provided by the doctor or nurse involved with the procedure.

**What possible side effects are there with PVP?**

Partial or complete pain relief can be achieved. Over 95% of people treated will have an excellent result. The pain relief happens quickly, usually within the first day. On rare occasions the pain will worsen for a few days before it gets better.

Since every patient’s condition is unique, the side effects will be different for each patient. Please ask your doctor for your specific side effects.

*Note, if you take Warfarin (Coumadin®) or any other blood thinner, please inform your doctor prior to the procedure.*
**Kyphoplasty:**

While PVP stabilizes and strengthens the building blocks of the spine, it may not restore the height or shape of the bone. If this is required, then Kyphoplasty may be used.

**What does Kyphoplasty involve?**

The next page will illustrate how a small balloon is introduced into the gap in the bone by a needle. The space made is filled with cement.

The Inflatable Bone Tamp (needle with balloon) is inserted into the fractured vertebral body.

The balloon is inflated, restoring vertebral body height, and making a hole in the vertebral body.
The hole is filled with bone cement.
These pictures were kindly provided by Medtronic of Canada Ltd.

More detailed instructions will be provided by the physician or nurse involved with the procedure.

**What possible side effects are there with Kyphoplasty?**

Since every patient’s condition is unique, the side effects will be different for each patient. Please ask your surgeon for your specific side effects.

**Cementoplasty:**

Cementoplasty is the stabilization of a bone anywhere else in the body by cement injection (i.e. other than the spine). This procedure can often lead to significant pain relief and improved mobility of the treated area within 24 hours.

**What does Cementoplasty involve?**

Cementoplasty is similar to PVP, except it can be used to treat other areas of the body, such as the hips, thighs and shoulders.
CT-guided cementoplasty of left pelvis bone metastases.

Cement is injected into the pelvis.

More detailed instructions will be provided by the doctor or nurse involved with the procedure.

**What possible side effects are there with Cementoplasty?**

Since every patient’s condition is unique, the side effects will be different for each patient. Please ask your doctor for your specific side effects.
Chemotherapy and Hormonal Therapy:

Chemotherapy (anticancer drugs of various types) and hormone therapy (used for certain types of cancer like breast and prostate) are both treatment options for bone metastases. The goals of these therapies are to control tumour growth, reduce pain, and reduce the risks of bone fractures. Your doctor will describe the best treatment options for your situation and what possible side effects you might expect.

Bisphosphonates:

Bisphosphonates are neither chemotherapy nor hormone therapy. They are medications that may help strengthen the bone, reduce pain, and reduce the possibility of the bone breaking. Bisphosphonates are used for certain stages of breast, multiple myeloma, lung and prostate cancers.

Some examples of commonly used bisphosphonates used in the treatment of bone metastases are: Pamidronate (Aredia®, Pamidronate Injection®) and zoledronic acid (Zometa®). Pamidronate and zoledronic acid are given through a drip into a vein in your arm. Clodronate (Bonefos®, Ostac®, Clasteon®) is a less commonly used bisphosphonate that is taken by mouth. Bisphosphonates including zoledronic acid, pamidronate, ibandronate, and clodronate reduce bone thinning in patients with bone metastases, delay the onset and reduce the risk of bone complications in multiple tumour types by 31% to 58%. The side effects of bisphosphonate therapy are usually very mild. They might include an upset stomach in the case of clodronate, and short-lived flu-like symptoms in the case of pamidronate and zoledronic acid. Bisphosphonates are given as often as needed and as long
as your doctor thinks is best for you. You might be given instructions to take calcium and vitamin D supplements during treatment with bisphosphonates.

**What do I need to know when taking bisphosphonates?**

1. Blood work is done often to watch for changes

2. Drink fluids often

3. Report any of these signs to your doctor or nurse:
   - Feeling sick to your stomach
   - Pain or swelling in the vein in your arm
   - Muscle stiffness
   - Confusion
   - Thirst
   - Change in how your foods taste
   - Pain when swallowing
   - Jaw pain

4. Follow a healthy diet and exercise as you are able

5. It is often recommended to see a dentist before starting bisphosphonates to make sure your jaw is healthy

**How long do I have to take Bisphosphonates?**

Your doctor may prescribe bisphosphonates when metastases are first found in your body or when your bone metastases cause pain. You may take them for several months or as long as your doctor thinks is best for you.
**Analgesics (Pain Medication):**

Your doctor will often prescribe pain medications as part of your treatment. Bone pain is best managed when pain medications are taken as they are prescribed. Please see the pain section (page 41) for guidance on how to take your pain medications to give you the best pain relief possible.

**Other Therapies:**

Apart from the listed therapies and physiotherapy, occupational therapy and psychotherapy, there are complementary and alternative therapies that may be available to you through the community. Examples of both are acupuncture and herbal medicines. **Please be sure to check with your physician or nurse before beginning any of these therapies.**

Other forms of support are art and music therapy, support groups, relaxation therapy, spiritual therapy and exercise programs. You may access these through your community if they are offered in your area. Please refer to the **Health Care Team** and **Resource** sections of the book for more details and contact information.

**New Advances:**

Please note, not all of these treatment options may be available at each cancer centre. The treatment of cancer that has spread to the spine (or "vertebrae") is often a multidisciplinary one. It can be better to combine treatments (e.g. surgery and radiation therapy and/or chemotherapy).
Surgery can stabilize an unstable spine. However, radiation or chemotherapy may additionally reduce the tumour size in the bone. In surgery, there are newer, easier ways that require less cutting of the skin to reduce the pressure off the spinal cord from the tumour and to stabilize the vertebrae, like "percutaneous vertebroplasty" (PVP) or "kyphoplasty".

Bisphosphonate therapy (similar to the drugs used in the treatment of osteoporosis or brittle bone) has also been of tremendous value in reducing bony pain.

Patients who have not previously been considered for surgery may now have that option. Additionally, we are now able to apply a much higher dose of radiation safely using "radiosurgery" in some situations. This allows us to target the radiation to the disease and to spare as much healthy, critical parts of the body as possible, such as the spinal cord.

Photodynamic therapy (PDT) is a treatment where a laser light is inserted down a hollow tube into the tumour in the vertebrae and light of a specific wavelength, when coupled with a "photosensitizer" drug, can destroy tumour locally. This can be used along with PVP or kyphoplasty. Your cancer health care team will discuss with you which is the best available treatment option.
How do I manage my pain?

In this section, we will describe the information about pain that is specific to bone metastases, different pain management options, myths about medications, how to use a pain diary, and some tips on how to handle some side effects of medications.

Pain from Bone Metastases

Bone metastases can cause pain that may become worse with certain movements. Patients with bone pain often describe it as a "dull aching" pain at rest and a “sharp” pain with movement. Bone pain tends to be located right over the area of the bone that is involved or may be referred to nearby parts of the body.

Some facts about you and your pain:

- Your pain is unique to you
- Your pain is whatever you say it is
- Your pain can be managed
- Managing your pain will improve your quality of life

What different pain management options are there?

Different types of medications may be used to treat bone pain. Examples include opioids, anti-inflammatories, and medications for nerve type pain.
**Opioids**

Opioids are medications like morphine, hydromorphone, oxycodone, fentanyl, methadone, and codeine. The old name for these is "narcotics". If you experience bone pain throughout the day, a combination of long-acting and short-acting opioids are suggested. These medications are taken on a routine or regular basis to give you the best pain relief.

Long-acting opioids (e.g., Codeine Contin, OxyContin®, MS Contin, Hydromorph Contin, Fentanyl patch like Fentanyl®) release pain medication slowly into your body. They are usually taken by mouth but other forms are available. Long-acting pills are taken every 8 or 12 hours.

Short-acting opioids (e.g., Codeine, Tylenol #1, 2, 3 or 4, Oxycodone like Percocet®, Morphine, Hydromorphone) release pain medication quickly into your body. These can be taken by mouth every hour or two as needed for “breakthrough” pain. This “breakthrough” pain is the pain you may feel in between doses of long-acting opioid(s).

It is safe to take long-acting and short-acting opioids together as prescribed by your doctor. When patients have mild pain, sometimes short acting opioids are all they need.

**What possible side effects are there from Opioids?**

The most common side effect of opioids is constipation. **All patients taking regular opioids should be taking regular laxatives.** Other common side effects include sedation, dry mouth, nausea, and vomiting. These side effects are
usually temporary and can be managed effectively by you and your health care team. Please see pages 44-47 for more information on opioid side effects and how to manage them.

**What are the common myths about taking Opioids?**

- Some patients worry they will become “addicted” to opioids if they take them regularly. Be reassured that in fact, the risk of addiction is extremely low in patients taking opioids for pain.
- Other patients worry that opioids are too “strong”, and should be reserved for very severe pain. Opioids are very effective at relieving bone pain and doses can be adjusted depending on the level of pain.

**Anti-inflammatory Medications**

These medications are often prescribed in addition to opioids. They help by reducing the inflammation or swelling that occurs around tumour cells in the bone. Examples of these medications include: Tylenol, Ibuprofen and corticosteroids (Dexamethasone).

**Medications for Nerve Pain**

Because there are many nerves in the body that travel near and through the bones, patients with cancer in their bone may experience pain from irritation of or damage to these nerves. This type of pain is often described as “stabbing”, “burning” or “radiating”. Medications that specifically address nerve pain may be added to the opioids you are taking. Examples of these medications include: Gabapentin, Pregabalin, Amitriptyline and Nortriptyline and other drugs.
Interventional Procedures for Pain Management

For a few patients, their bone pain is not taken away completely by radiation and/or medications. If this is the case for you, your doctor may suggest you see an “interventional pain specialist” (often a radiologist or an anesthesiologist). These doctors can offer to perform special procedures like nerve blocks.

What are the common side effects from the pain medications and how do I manage them?

**Constipation**

Constipation is the most common side effect of opioid medication. Constipation means your bowel movements are not as frequent and can be too small, too hard or too difficult to pass on a regular basis compared to what is normal for you.

Unlike other side effects such as feeling sick to your stomach or feeling drowsy, constipation will not improve with time on its own. You need to take laxatives regularly as recommended by your doctor.

How do I manage constipation?

Your doctor will give you laxatives to take as soon as you begin taking your pain medication. **It is important to take laxatives on a daily basis if you are using opioids.** Some common laxatives include: Senokot® (sennosides), Dulcolax® (bisacodyl), Milk of Magnesia®, Ducosate Sodium® (Colace) and Lactulose®.
Your physician or nurse will give you instructions about how to take laxatives.

What are the important things to remember to do when taking laxatives?

Information to keep in mind when taking laxatives:

- Take laxatives every day even when your bowels are working
- Drink fluids frequently every day (usually around 6-8 8oz glasses of non-alcoholic, non-caffeinated beverages each day)
- If you can (when your constipation is controlled), eat foods high in fibre (for example, fresh fruits, vegetables, bran cereals, whole grain products)
- Talk to your nurse or doctor if you are having problems with constipation

Nausea and Vomiting

Nausea (feeling sick to your stomach) and vomiting (the emptying of the stomach contents through the mouth) occurs in one-third of people taking opioids. These side effects are usually temporary and pass within 3-4 days of starting the opioid. Your doctor can give you medications to treat both. Over time, your stomach will settle as your body gets used to your pain medications. If your nausea and vomiting stops you from eating, drinking or taking medications, please tell your doctor or nurse.
How do I manage nausea?

- Drink clear, cold fluids
- Have several small meals a day and eat slowly
- Try eating bland foods or dry starchy foods (e.g. crackers and toast) at room temperature
- After eating, do not lie down flat
- Keep a basin handy, in case you want to vomit
- Inform your doctor or nurse if nausea is severe and lasts longer than 48 hours, or prevents you from eating, drinking or taking medications

How do I manage vomiting?

- Take prescribed medication for vomiting
- If you can’t take pills, a suppository may help
- Inform your doctor or nurse if you have vomited several times a day and if it has lasted more than 24 hours
- Try to drink plenty of clear fluids if you are able to
- Slowly begin eating bland food when you feel able to keep food down

Drowsiness

Feeling drowsy is common for most people who first begin taking opioids. It usually lasts for 3 or 4 days and then goes away. This may happen again if the dose of your pain medications increased. If drowsiness does not improve or worsens after you have been taking the same dose of opioids for some time, please call your nurse or doctor. Your doctor may need to adjust the dose of your opioids.
Sudden Muscular Contractions

A sudden shaking or jerking of the hand, arm, or leg can occur sometimes when taking opioids. Please report these to your nurse or doctor.

Dry Mouth

Having dry mouth is a common side effect among patients taking opioids. It tends to continue as long as you are on opioids. To help manage dry mouth, try chewing sugar free gum or sucking on sugar free hard candies to help encourage saliva. Also try drinking more fluids.

What is a Pain Diary?

A Pain Diary is a way to record the pain you experience on a day-to-day basis. It is to help you and your cancer health care team make sure that your pain is well managed.

Why use a pain diary?

Patients, caregivers and family members find a pain diary helpful because:

- It can help you tell your doctor or nurse about your pain
- It can give you a sense of control of how to better manage your pain
- It can make you more aware of your pain
- It can help you decide what dose is best for you
- It can help you decide how to change your actions
- It can help you communicate about your pain with family members
One patient said:

“It made me aware of how important it is to control my pain very well, so I can live my life. My diary gives a picture of what each day is like for me. It allows my doctors and nurses to make suggestions that help make sure the pain doesn’t keep me from doing what I want to do.”

One caregiver said:

“The diary was helpful because it helped me keep track of when I gave him things. It also helped me to understand my husband’s feeling about his pain and how bad it was.”

The goal of a pain management plan is to control the pain well. A pain diary is an excellent way of helping achieve this.

**How do I use the Pain Diary?**

At bedtime, think about your pain throughout the day and using the 0-10 number scale, write down your pain at its worst, least and average level (0 is no pain and 10 is the worst pain ever). Feel free to add in comments like “very active this morning” or “in bed most of the day”.

Complete your medicine section on the next page. Write your long-acting and short-acting pain pills, the amount, and the time under Regular and Breakthrough Medication table. Write the name of “other” medications you have been prescribed, (Laxatives, anti-nausea medication etc.), the amount, and the time under Other Medication table.
A sample of how to fill out the pain diary sheet is provided on the next page to help you. You may copy diary sheets from this book if you need extras.

Please bring these diary sheets to your next doctor’s appointment.
Pain Diary (example)

Date: **July 7th, 2008**

I have felt pain in the following areas over the last **24 hours** (list all):

Shoulder, low back and right thigh

Please rate your pain by circling the one number that best describes your pain at its **worst** during the past **24 hours**.

<table>
<thead>
<tr>
<th>No Pain</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Worst Pain Ever</th>
</tr>
</thead>
</table>

Please rate your pain by circling the one number that best describes your pain at its **average** during the past **24 hours**.

<table>
<thead>
<tr>
<th>No Pain</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Worst Pain Ever</th>
</tr>
</thead>
</table>

Please rate your pain by circling the one number that best describes your pain at its **least** during the past **24 hours**.

<table>
<thead>
<tr>
<th>No Pain</th>
<th>0</th>
<th>1</th>
<th>2</th>
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<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Worst Pain Ever</th>
</tr>
</thead>
</table>

Comments:

My low back was hurting the worst out of the three, especially when I lay down on the bed. The pain was dull and achy and kept me up at night.
Please write **ALL** **REGULAR** and **BREAKTHROUGH** pain medications you have been taking during the past **24 hours**.

Note: If using a fentanyl patch, or “Duragesic”, please indicate strength of each patch.

<table>
<thead>
<tr>
<th>Name of Medication</th>
<th>Strength (mg)</th>
<th>Time taken</th>
<th>Regular or Breakthrough pain medication &amp; How many?</th>
</tr>
</thead>
<tbody>
<tr>
<td>MS Contin</td>
<td>15 mg</td>
<td>8am</td>
<td>Regular (2 pills)</td>
</tr>
<tr>
<td>Tylenol Extra Strength</td>
<td>500 mg</td>
<td>10am, 4pm</td>
<td>Breakthrough (1 pill)</td>
</tr>
<tr>
<td>MS Contin</td>
<td>15 mg</td>
<td>8pm</td>
<td>Regular (2 pills)</td>
</tr>
</tbody>
</table>

Please write **ALL** the **OTHER** medications you have been taking during the past **24 hours**.

<table>
<thead>
<tr>
<th>Name of Medication</th>
<th>Strength (mg)</th>
<th>Time taken &amp; How many?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Senokot</td>
<td>8.6 mg</td>
<td>8am (1 pill) 10pm (1 pill)</td>
</tr>
</tbody>
</table>

Any side effects?: **Still had constipation**
Date: MM/DD/YYYY

I have felt pain in the following areas over the last **24 hours** (list all):

Please rate your pain by circling the one number that best describes your pain at its **WORST** during the past **24 hours**.

<table>
<thead>
<tr>
<th>No Pain</th>
<th>0</th>
<th>1</th>
<th>2</th>
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<th>9</th>
<th>10</th>
<th>Worst Pain Ever</th>
</tr>
</thead>
</table>

Please rate your pain by circling the one number that best describes your pain at its **AVERAGE** during the past **24 hours**.

<table>
<thead>
<tr>
<th>No Pain</th>
<th>0</th>
<th>1</th>
<th>2</th>
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<th>5</th>
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<th>8</th>
<th>9</th>
<th>10</th>
<th>Worst Pain Ever</th>
</tr>
</thead>
</table>

Please rate your pain by circling the one number that best describes your pain at its **LEAST** during the past **24 hours**.

<table>
<thead>
<tr>
<th>No Pain</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Worst Pain Ever</th>
</tr>
</thead>
</table>

Comments:
Please write ALL **regular** and **breakthrough** pain medications you have been taking during the past 24 hours.

Note: If using a fentanyl patch, or “Duragesic”, please indicate strength of each patch.

<table>
<thead>
<tr>
<th>Name of Medication</th>
<th>Strength (mg)</th>
<th>Time taken</th>
<th>Regular or Breakthrough pain medication &amp; How many?</th>
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</table>

Please write ALL the **other** medications you have been taking during the past 24 hours.

<table>
<thead>
<tr>
<th>Name of Medication</th>
<th>Strength (mg)</th>
<th>Time taken</th>
<th>Time taken &amp; How many?</th>
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</table>

Any side effects?
Date: MM/DD/YYYY

I have felt pain in the following areas over the last 24 hours (list all):

Please rate your pain by circling the one number that best describes your pain at its **WORST** during the past 24 hours.

<table>
<thead>
<tr>
<th>No Pain</th>
<th>0</th>
<th>1</th>
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<th>3</th>
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<th>9</th>
<th>10</th>
<th>Worst Pain Ever</th>
</tr>
</thead>
</table>

Please rate your pain by circling the one number that best describes your pain at its **AVERAGE** during the past 24 hours.

<table>
<thead>
<tr>
<th>No Pain</th>
<th>0</th>
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<th>8</th>
<th>9</th>
<th>10</th>
<th>Worst Pain Ever</th>
</tr>
</thead>
</table>

Please rate your pain by circling the one number that best describes your pain at its **LEAST** during the past 24 hours.

<table>
<thead>
<tr>
<th>No Pain</th>
<th>0</th>
<th>1</th>
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<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>Worst Pain Ever</th>
</tr>
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</table>

Comments:
Please write **ALL** **REGULAR** and **BREAKTHROUGH** pain medications you have been taking during the past **24 hours**.

Note: If using a fentanyl patch, or “Duragesic”, please indicate strength of each patch.

<table>
<thead>
<tr>
<th>Name of Medication</th>
<th>Strength (mg)</th>
<th>Time taken</th>
<th>Regular or Breakthrough pain medication &amp; How many?</th>
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</tbody>
</table>

Please write **ALL** the **OTHER** medications you have been taking during the past **24 hours**.

<table>
<thead>
<tr>
<th>Name of Medication</th>
<th>Strength (mg)</th>
<th>Time taken</th>
<th>Time taken &amp; How many?</th>
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</table>

Any side effects?
Date: MM/DD/YYYY

I have felt pain in the following areas over the last **24 hours** (list all):

Please rate your pain by circling the one number that best describes your pain at its **worse** during the past **24 hours**.

<table>
<thead>
<tr>
<th>No Pain</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<th>9</th>
<th>10</th>
<th>Worst Pain Ever</th>
</tr>
</thead>
</table>

Please rate your pain by circling the one number that best describes your pain at its **average** during the past **24 hours**.

<table>
<thead>
<tr>
<th>No Pain</th>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
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<th>10</th>
<th>Worst Pain Ever</th>
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</table>

Please rate your pain by circling the one number that best describes your pain at its **least** during the past **24 hours**.

<table>
<thead>
<tr>
<th>No Pain</th>
<th>0</th>
<th>1</th>
<th>2</th>
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<th>8</th>
<th>9</th>
<th>10</th>
<th>Worst Pain Ever</th>
</tr>
</thead>
</table>

Comments:
Please write **ALL** *regular* and *breakthrough* pain medications you have been taking during the past **24 hours**.

Note: If using a fentanyl patch, or “Duragesic”, please indicate strength of each patch.

<table>
<thead>
<tr>
<th>Name of Medication</th>
<th>Strength (mg)</th>
<th>Time taken</th>
<th>Regular or Breakthrough pain medication &amp; How many?</th>
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Please write **ALL** the *other* medications you have been taking during the past **24 hours**.

<table>
<thead>
<tr>
<th>Name of Medication</th>
<th>Strength (mg)</th>
<th>Time taken</th>
<th>Time taken &amp; How many?</th>
</tr>
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Any side effects?
Why am I feeling so tired all the time?

Fatigue is one of the most common and bothersome symptoms associated with cancer. Patients sometimes use words such as “exhausted”, “tired” and “weak” to describe the feelings of fatigue. Patients will sometimes say: “I feel weak all over”; “I cannot take another step”; “I have no energy at all”.

However, fatigue in cancer is more than feeling tired. With cancer and cancer treatment, the feeling of fatigue does not go away after a rest or a good night sleep. Some of the signs of fatigue that can be experienced include getting tired quickly after doing normal things like taking a shower, cooking, going for a short walk, or climbing stairs. Some people find they have difficulty concentrating or remembering details.

When fatigue is present, it may make it difficult to complete usual daily activities, work or leisure activities. It can impact how a person interacts with family and friends. If severe, it can impact whether a person completes treatment and their quality of life. Experiencing fatigue is often accompanied with feelings of frustration and emotional distress.
What causes fatigue?

Fatigue is a complex symptom and is not well understood. However, some of its causes are known and some of these are treatable. Factors that contribute to fatigue are:

- The effect of cancer on a body’s metabolism and nutritional state
- A low blood count
- The effects of chemotherapy and radiation therapy
- Medications (such as pain-killers or anti-nausea medications)
- Infections (such as pneumonia)
- General muscle weakness and inactivity
- Disturbed sleep patterns
- Feelings of sadness or anxiety
- Other symptoms (such as pain or shortness of breath)

How is fatigue treated?

Fatigue is addressed most effectively by tailoring the treatment to the individual patient. Each situation is unique and what is helpful in one situation can be less so in another. Treatment is generally aimed at causes that can be reversed. Therefore, a good assessment of the fatigue and how it impacts the person is the first step.

Possible treatment options may include:

- Energy conservation techniques
- Light exercise as able
- Alterations in diet
• Alteration in medications that can contribute to fatigue
• Stimulant medications (if appropriate)
• Correct low blood counts, or "anemia" (if present)

What happens if the fatigue does not go away or the treatments do not help?

In situations where the fatigue does not improve, finding ways to cope with the fatigue becomes a new goal. Some patients have found the following ideas useful:

• Set realistic goals for daily activity based on how you feel and where you are in treatment
• Let family and friends help with the activities that are most tiring (i.e., housework, getting meals, grocery shopping, yard work)
• Schedule important activities during the time of the day when your energy is highest
• Consider new activities that are less tiring (i.e., reading, keeping a journal, painting, scrap-booking, listening to music)

Tips on Managing your Fatigue

The goal in managing fatigue is to help you enjoy the things you like to do. Here are some tips that may be of use:

• Drink enough fluids
• Work to have balanced nutrition (a Registered Dietician can help with this)
• Pace your activities and take a short rest after each if needed
• Plan for short daily exercise sessions as you are able
• Do the things that give you joy and pleasure first if you can
• Divide the activity you like into stages and rest between stages if you need
• Sit rather than stand when you cook, shave, shower or brush your teeth
• Organize things so that they are within easy reach
• Pay attention to temperatures (cool in your home, warm not hot baths)
• Organize and maintain a consistent routine for going to sleep
• Talk with your nurse or doctor if you are feeling sad, worried or frustrated

If you have questions about any of these tips, please talk with your nurse or doctor about them. Members of your health care team will be able to direct you to resources that may be of additional assistance.
How am I feeling?

Finding out you have bone metastases can be a difficult time for you or your family members. There can be feelings of worry or fear. There can be feelings of uncertainty about what is happening. Some individuals cannot concentrate and have difficulty sleeping. Others experience a sense of helplessness.

What can I do about the feelings I have?

Your doctor and nurse can help you deal with the feelings you may now be experiencing. They can be helpful in providing emotional support to you if you let them know how you are feeling. Some patients have also found it helpful to do the following:

- Learn as much as possible about the disease and treatment options
- Ask the doctor any questions about the treatment
- Write down any concerns you have and talk about them with the nurse or the doctor
- Talk with other individuals who have gone through the same experiences

Many cancer patients find it is easier to cope with the situation when they understand what is happening to them and are able to share their feelings with others.
What is coping?

Coping describes the ways that people manage or deal with the things that happen in their lives. It is about how people make decisions about what to do and how to act.

You may have worries about how you will manage on a day-to-day basis and how your lifestyle and finances will be affected. Will you be able to do all the things you normally do? Will you be able to go to work or do the house or yard cleaning? What help will you need from others? How do you ask for help if they need it?

Patients also may feel emotional distress if they are worrying that their cancer is aggressive and their life expectancy is short.

How do I cope with the situation?

How people cope with these worries and day-to-day responsibilities will vary from person to person. Every person will cope in a different way. But it is important to realize that there is no one right or wrong way to manage this situation.

People often draw on their past experiences to help them cope. For some people, their past life experiences give them strength and courage to help them deal with current events. They may see this illness as another life challenge. Others may find their experiences in the past did not help prepare them for this one. You may need to learn new ways to manage or cope and you may need additional help.
Individuals who find it difficult to cope may find it helpful to talk with the care team. Speaking with professionals about what it means to live with bone metastases and the impact that they have each day can be useful. There are assistance programs and services that can be arranged to help you at home.

Other people may benefit from having a conversation with a counselor or an individual who specializes in helping people manage emotional distress. The health care team has social workers, nurses, and psychologists who are familiar with bone metastases and can provide advice (You can speak to your doctor or nurse about referrals that may be helpful).

**What coping strategies can be helpful?**

People will use different strategies to cope with their illness. Here are some that others have found helpful.

**Obtaining Information:** Some people feel it is useful to obtain as much information as possible about the disease, the treatments, and the resources available.

**Talking with Others:** Talking with other cancer patients can be useful to share feelings and to gather helpful tips. It also helps you know you are not alone, and there are others who have travelled a similar journey.

**Turning to Family and Friends for Help:** Some people feel that their link or bond with their family and/or friends is an important source of support. Working out who is going to do which activities and making a plan about roles and responsibilities together can be useful.
Finding ways to do what is important to you: People feel a sense of well-being and self-worth if they are able to continue to contribute to their family and to their community. It is part of what helps us feel we are valued. People need to think about what is important to continue (i.e., work, volunteer activities, religious activities). Once they have decided what is important, special plans or arrangements may need to be made. For example, these could include conserving energy for important events, planning daily activities with “rest” breaks, arranging transportation.

Asking the Health Care Team about Resources: The health care team knows about available resources that can assist you and can provide a list of available services in your community (i.e., support programs, home care services, transportation services, advanced care planning, etc.)

Commonly Experienced Thoughts and Concerns: Living each day to the fullest

Many individuals with bone metastases find they are thinking more and more about how to live each day to the fullest. Many talk about how special their family is and the joys they find in doing simple daily chores.

One man stated,

“I now cherish the talks I have with my wife and teenagers. I used to be so focused on my kids doing well in school and helping with the household chores – now none of that seems to matter. I treasure the closeness we feel as a family.”
A woman indicated,

“I have learned to leave the dishes in the sink when something beautiful or enjoyable comes along. The dishes will not go anywhere, but the time to sit and talk with my grandchildren may pass...and the drives in the country with my husband are glorious now that it is summer.”

**Loss of independence and being a burden**

One of the concerns individuals have when they feel their independence is decreasing, is that they will become a burden to their spouse, family members or friends. Most people are used to being able to do things for themselves and find it a challenge to discover they are not able to continue at the same level of activity.

A gentleman stated,

“I love to do woodwork. I have a rather large workshop in the basement and used to spend so many hours in it. Now I find I cannot keep it up the way I used to, I have to pace myself...and I am thinking that I will have to find another solution in the future.”

Meanwhile, a woman said,

“I cannot do the housework. I have to ask my daughter to help. And that makes me uncomfortable. I really like to do things on my own.”
Fear of dying

A common concern among most patients living with bone metastases is a fear of dying earlier than one expects.

One patient stated,

“I do think about dying and about death... and how it is somehow unfair and not supposed to happen to me, not now when I am in my prime.”

What can be done to help?

Most people find it helpful to be given a chance to talk about their concerns openly with their health care team. It can be hard to find a way to begin to talk about these concerns at first. However, once patients begin to talk about death and dying with a member of the health care team, they often feel less worried. They know someone is listening and learn what they can expect from the illness.

It is important to realize that some may not wish to talk about dying. Everyone finds their own level of comfort about talking. Each person will make their own decision regarding what they will talk about with the health care team and what they do not wish to share. Some will choose to talk with another person in the community.

Why is it important to cope with pain and loss of movement?

Pain and loss of movement are two symptoms that often concern people who live with bone metastases. If pain remains uncontrolled, it can be distressing and can also lead to loss of movement. A person may then feel added anxiety and distress.
Every person copes with pain in his or her own way. Some people think of the pain as a life challenge and work at controlling the pain. Others see the pain as a loss. If the pain limits what they can do. If uncontrolled, pain can also lead to sleeping and concentration difficulties. Careful assessment of pain and appropriate intervention by the health care team can assist in finding the best way to control pain.

Loss of movement often means that one has a harder time caring for themselves on a daily basis. Many individuals are used to looking after themselves in some way and doing the things they like to do. When there is a loss of movement and a decreasing ability to do what is desired, it can be helpful to sit down with family members and talk about alternatives.

For example, one gentleman talked with his family about how much he loved gardening, but now he finds it too hard to do. Instead, he listens to the daily garden programs on the radio. He grows his plants in his indoor window boxes. As a result, he can still enjoy his hobby despite not being able to manage the outdoors any more.
In this section, you can use the legend below to see which health care professional may be able to help you with the topics discussed. Each section of the book is colour and shape coded for easy referral.

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Your Health Care Team

Who is my Cancer Health Care Team?

Since cancer may require a complicated diagnosis and treatment process, there will be a team of health professionals involved in your care. Each team member has special skills that bring a unique touch and perspective to your care.

Please remember that there are varied ways that cancer care is delivered across Canada, so your province health care team and their roles and responsibilities may differ from the ones listed here. Please also note that some health care professionals listed below may be available in the community and not just in the cancer centre or hospital. The following is an alphabetical list of some of the health care professionals who may be involved in your care.

Chaplain

Spiritual care is an important part of the holistic approach to healthcare. Spiritual care affirms the dignity and value of all persons and respects different spiritual views and practices which may, or may not be rooted in religious tradition. Spiritual care professionals (Chaplains) are here for you and your family. Chaplains can ensure that your spiritual needs are addressed in your healthcare plan. As well, Chaplains can provide support for your loved ones. Religious care is a form of spiritual care that is provided from within a specific religious tradition.
Chaplains offer:

- Crisis intervention and support
- Guidance and support through challenging ethical and moral decision-making processes
- Facilitation of religious rituals, meditation and prayer
- Access to Religious Care Providers, communities and resources from various traditions
- Consultation on multi-faith and diversity issues, spiritual assessment and intervention
- End-of-life, grief and bereavement care and counselling
- Mediation support in situations of conflict

Chaplains are available for you and your family. Anyone can request to speak with a Chaplain at any time or simply ask your health care team to make a referral.

**Dietitian**

Registered Dietitians are trained professionals who can advise you on diet, food and nutrition. Dietitians counsel patients on healthy eating and dealing with nutrition challenges. Dietitians can give you ideas for eating well to help maintain your energy and quality of life, as well as strategies for dealing with any eating difficulties you may have.

Dietitians can help:

- Manage nutrition related side effects experienced from cancer and treatment.
- Maintain or improve nutritional status, lean body mass and the ability to carry out daily activities prior to, during and after cancer treatment.
- Improve strength, well being and quality of life.
As treatments and side effects are different for each person with cancer, so are nutritional needs. Registered Dietitians are available to provide individual care to patients or their families/caregivers. You can request to speak with a Dietician or your Medical or Nursing team can make a referral.

Home Care nutrition consultations are available in some areas. To access this service, contact your local home care coordinating services or speak with a social worker. If you are not enrolled on home care, contact Dietitians of Canada to access a consulting Dietitian (Please refer to RESOURCES section for contact information).

**Occupational Therapist**

An occupational therapist is a health care professional who can assist you to safely maximize your independence in your daily activities. These may be activities related to caring for yourself, managing tasks in your home or at your job, or what you enjoy doing in your spare time.

Occupational therapist may be able to:

- Make some suggestions for different or alternate ways for carrying out these activities, including recommendations for equipment to make these activities easier and safer for you. For example, use of safety rails in the bathroom, shower chair or bench, toilet raiser etc.
- Discuss energy conservation strategies to help you manage feelings of fatigue. For example, prioritizing what matters most to you, what needs to be done, and when best to do it.
• Provide education to help you and your family understand how to live as normally as possible
• Visit you in your home to suggest any home environment alterations to ensure that you are as safe and independent as possible

To see or speak to an occupational therapist, please talk with your doctor or nurse who may be able to refer you to an occupational therapist in the Cancer Centre, the local hospital, or in the community.

**Family Physician (General Practitioner)**

A family physician provides primary care to patients, assesses overall health, treats acute and chronic illnesses and refers patients to specialists on an ongoing basis. Family physicians continue to see patients throughout their cancer treatment and will be kept informed by the oncologists regarding their cancer care.

**Oncologists**

Oncologists are physicians that specialize in cancer care. There are several different types of oncologists. A *surgical oncologist* is a surgeon that specializes in the treatment of cancer by removing the tumour from the body. A *medical oncologist* is a physician that specializes in the treatment of cancer with the use of drugs. Some examples are chemotherapy, hormonal therapy and bisphosphonates. A *radiation oncologist* is a physician that specializes in the treatment of cancer through the use of radiation.
Oncology nurses will be monitoring your condition closely, especially your symptoms and their impact on your daily living. They can assist you in planning how to make adjustments in your daily life and provide help with managing the symptoms that bother you. Oncology nurses are in regular contact with the oncologists and can convey any questions or concerns you may have, and inform them of any changes in your condition. You will encounter a few nurses and there may be a primary oncology nurse assigned to you. Oncology nurses provide information, answer many of your questions, deliver chemotherapy and bisphosphonates, and provide support and day-to-day care to cancer patients. They can also connect you with other members of the cancer health care team.

Palliative Care Consult Team (PCCT)

The Palliative Care Consult Team (PCCT) is a group of health care professionals working to provide pain and symptom management regardless of stage of disease. They aim to improve the quality of living and dying for patients and their families coping with challenging, advanced or life threatening illness.

Palliative care is a field of healthcare that is committed to promoting the best possible quality of life for patients. Palliative care involves excellent pain and symptom management, as well as skills in assessing psychosocial, emotional, and spiritual needs of patients and their loved ones. Doctors, nurses, social workers, pharmacists,
rehabilitation professionals and spiritual care specialists can each have special expertise within the field.

Please note that not all hospitals or cancer centres will have a Palliative Care Consult Team.

**Pathologist**

A pathologist is a physician that looks at tissues from a biopsy, blood or other body fluids under a microscope to determine if there are any abnormal cancer cells present and to observe how they might behave.

**Pharmacist**

A pharmacist is a health care professional that specializes in preparing and dispensing prescriptions during cancer treatment including chemotherapy and radiation. Pharmacists fill prescriptions, give verbal and written instructions for taking medications, give advice on managing side-effects and help answer questions about the drugs.

**Physiotherapist**

A Physiotherapist has specialized knowledge on the function and movements of the human body, and an in-depth understanding of how to restore mobility.

Physiotherapists manage and prevent physical issues caused by disease, illness, aging, inactivity, as well as sport and work related injuries.

Physiotherapists can also work to prevent fractures. They assess and adapt mobility to help with stability and safe movements of patients, as well as recommend walking
devices when appropriate. Physiotherapists also work to strengthen the structures (i.e. muscles etc.) around the bone affected with a metastasis, as well as work with patients to rehabilitate after the treatment of these fractures.

It is important to note that physiotherapists do not directly treat fractures, and should you suspect a fracture, you should contact your physician or nurse and go immediately to the nearest emergency department.

Physiotherapists also educate patients and their families regarding the risks, signs and symptoms of fractures.

To see or speak to a physiotherapist, please talk with your doctor or nurse who may be able to refer you to a physiotherapist in the Cancer Centre, the local hospital, or in the community.

**Psychologist**

A psychologist is a mental health care professional who can help you and those who care for you with the complex emotional aspects of cancer.

A clinical psychologist provides:
- Adjustment counselling related to the cancer for both patients and those caring for them
- Psychosocial assessment
- In depth psychotherapy for broader and more complex personal and interpersonal issues
- Stress reduction, anxiety management, and relaxation training
- Couples counselling and communication training
• Grief and bereavement counselling
• Support around lifestyle change

Clinical Psychologists may be available at your cancer centre. Ask a member of your cancer care team for a referral. Psychologists locally may also be in private practice and the cost may be covered by your extended health plan. (Please refer to RESOURCES section for contact information).

Radiation Therapist
Radiation therapists are health care professionals that work with Radiation Oncologists to carry out the planning or simulation, calculations and delivery of the radiation treatment prescribed to you by the radiation oncologist.

Radiologist
A radiologist is a physician who interprets various types of scans, such as x-rays, CT scans and MRI scans. An Interventional Radiologist is a radiologist that specializes in minimally invasive procedures with the help of image guidance, such as CT or MRI scans.

Social Worker
A cancer diagnosis brings with it new feelings and experiences. Talking to a professional who has helped other people manage similar situations may help you and your family to cope with these feelings and concerns. An oncology social worker provides emotional, adjustment and resource support. Social work assessment and intervention is available throughout the stages of cancer care, including diagnosis, treatment, remission, recurrence and end-of-life care. Oncology social workers are uniquely qualified by their
knowledge of community resources and advocacy skills to act as a referral source to a variety of agencies and can help plan for future care needs. Ask your doctor for a referral to a social worker.

**Surgeon**

A surgeon is a physician that specializes in performing surgery. There are several different types of surgeons who may be a part of your cancer health care team. A *surgical oncologist* is a surgeon that specializes in the treatment of cancer by removing the tumour from the body. An *Orthopedic Surgeon* is a surgeon that specializes in musculoskeletal concerns; some examples are fractures, arthritis, or injuries. Some surgeons specialize in different areas of the body, such as spinal surgeons, knee surgeons, hip surgeons etc. The surgeon you see may not be the person who does your final surgery, however you will be referred to the best surgeon to treat your condition.
Medical Diary

Personal Information

Name:
Address:
Phone:
Hospital being treated:
Hospital ID Number:

Medical History

Type of cancer:
Date of Diagnosis (Primary):
Date of Diagnosis (Bone Metastases):

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Other Important Health Issues:
Your Cancer Health Care Team:

**FAMILY PHYSICIAN:**
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**MEDICAL ONCOLOGIST:**
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Phone:
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**RADIATION ONCOLOGIST:**
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Phone:
E-Mail:

**SURGICAL ONCOLOGIST/ORTHOPEDIC SURGEON:**
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This section contains some resources that may be useful. Some of these resources can only be found in certain provinces; please refer to the national contact information if you would like more details. You may ask for more information from your health care team. We do not necessarily endorse anything found on these websites.

**General Information on Cancer**

**Canada**

**Canadian Cancer Society (CCS)**  
http://www.cancer.ca  
Tel: 1-888-939-3333  
CCS provides information on types of cancers, prevention, advocacy and support. They also provide many free services such as transportation and wigs.

**Canadian Health Network (CHS)**  
http://www.canadian-health-network.ca  
CHS provides information about health promotion and prevention.

**Dietitians of Canada**  
http://www.dietitians.ca  
Tel: (416) 596-0857  
Contains Nutritional information and nutrition professionals.

**Guide to Internet Resources for Cancer**  
http://www.cancerindex.org  
Provides an easy way of finding specific cancer information.
Health Canada
http://www.hc-sc.gc.ca
Contains regulatory information on Natural Health products and the Natural Health Products Directorate.

National Cancer Institute (U.S.A)
http://www.cancer.gov/
Provides cancer related health information on a wide range of topics.

National Comprehensive Cancer Network
http://www.nccn.org
A network of 21 of the world’s leading cancer centres provides cancer treatment guidelines.

Ontario Cancer Research Network
http://www.ocrn.on.ca
Provides information on current research in prevention, early detection, diagnosis and treatment of cancer.

People Living with Cancer
http://www.plwc.org
Provides information about cancer, diagnosis, treatment and coping.

Provincial

Alberta Cancer Board
http://www.cancerboard.ab.ca
Tel: (780) 643-4500
Contains information on cancer for patients and family members and information on different cancer centres across Alberta.
BC Cancer Agency
http://www.bccancer.bc.ca
Tel: 1-800-663-3333
Contains information on cancer and on research and different cancer centres across British Columbia.

CancerCare Manitoba
http://www.cancercare.mb.ca
Tel: 1-866-561-1026
Contains information on cancer, resources and cancer centres across Manitoba.

Atlantic Health Sciences Corporation (New Brunswick)
http://www.ahsc.health.nb.ca
Contains general health and cancer information for different hospitals and cancer centres in New Brunswick.

Newfoundland Cancer Treatment and Research Foundation
http://www.cancer.ca
Contains information on cancer, on research and different cancer centres across Newfoundland.

Cancer Care Nova Scotia
http://www.cancercare.ns.ca
Tel: 1-866-599-2267
Contains information on cancer and on different cancer centres across Nova Scotia.

Cancer Care Ontario (CCO)
http://www.cancercare.on.ca
Tel: 416-971-9800
Provides information on cancer services in Ontario.
PEI Cancer Treatment Centre (Queen Elizabeth Hospital)
http://www.cancercentre.pe.ca
Tel: (902) 894-2946
Contains information on the facilities, links and different programs available.

Quebec Cancer Foundation (Fondation Quebecoise du Cancer)
http://www.fqc.qc.ca
Contains information on cancer and on different cancer centres across Quebec.

Saskatchewan Cancer Agency
http://www.saskcancer.ca
Tel: (306) 585-1831
Provides information on cancer, on resources and different cancer centres across Saskatchewan.

LOCAL COMMUNITY RESOURCES

Gilda's Club
http://www.gildasclub.org
Tel: 1-888-445-3248
Provide resources to help with emotional and social support for cancer patients and family members

Ontario Association of Community Care Access Centres (CCAC)
http://www.ccac-ont.ca
Tel: (416) 750-1720
Describes what CCAC service provides (i.e. Home Care) and how to locate a centre in your area.
Ontario Association of Social Workers
http://www.oasw.org
Tel: (416) 923-5279
Provides information on social workers and assistance with finding one in your area. Social workers that work with oncology population may be able to provide you with more specialized assistance.

Ontario Psychological Association
http://www.psych.on.ca
Tel: (416) 961-5552
Provides a resource on the practice and science of psychology. It also gives information about referrals and how to access a psychologist.

Trillium Drug Program
Tel: 1-800-575-5386
The Trillium Drug Program (TDP) is intended for Ontario residents who have a valid Ontario Health Card (with or without coverage) and who have high prescription drug costs in relation to their net household income. Please visit their website or speak to a social worker for more information.

Wellspring
http://www.wellspring.ca
Tel: 1-877-499-9904
Wellspring is a network of centres providing a wide range of cancer support programs and services, at no charge, to meet the emotional, social, psychological and informational needs of people living with cancer and those who care for them.
Palliative Care

Caring to the End of Life
http://www.caringtotheend.ca
Contains palliative care information for patients, caregivers and health care professionals in the Greater Toronto Area.

Halton Peel Palliative Network
http://www.hppcn.ca
Tel: 1-800-426-9666
Contains information regarding the resources and services available in the Halton and Peel Regions.

Hospice Association of Ontario
http://www.hospice.on.ca/
Tel: 1-800-349-3111
The Hospice Association of Ontario (HAO) is Canada’s largest volunteer hospice organization, consisting of more than 180 community-based volunteer organizations providing high-quality, compassionate end-of-life care for individuals living with a life-threatening illness, and those who care for them.

Virtual Hospice
http://www.virtualhospice.ca
Tel: 1-866-288-4803
Contains information and resources to help people understand the physical, emotional and spiritual aspect of cancer.
Glossary
Key Medical Terms

**Analgesics:** medications that are used to help with pain (also known as painkillers)

**Anemia:** a condition that has not enough healthy red blood cells to carry oxygen to your tissues

**Anesthesiologist:** a physician who gives drugs to patients to relieve pain and sensations, monitor patients during and after surgical procedures

**Anti-Inflammatory Medications:** medications that help decrease swelling around tumours or injury

**Biopsy:** a medical test that involves the removal of body tissue or cells for examination

**Bisphosphonates:** drugs that help prevent or delay bone complications that may occur from bone metastases

**Bone Metastases:** cancer that has spread from the primary (original) tumour to the bone

**Bone Scan:** a medical imaging method that uses a small amount of radioactive dye to detect the presence and extent of abnormalities in the bone, such as metastases. Usually takes approximately 4.5-5 hours to complete.

**Breakthrough Pain:** is when a patient with pain experiences intermittent flares of pain even when on regular analgesic medication

**Breakthrough Pain Medication:** medications that are quick acting to help relieve breakthrough pain
**Cancer:** an abnormal growth of cells, also known as a malignant tumour

**Cementoplasty:** a minimally invasive procedure that uses bone cement to stabilize a bone weakened by a metastasis

**Chaplains:** are spiritual care professionals who ensure that your spiritual needs are addressed

**Chemotherapy:** a treatment for cancer using drugs that attack all cells in your body, especially cancer cells

**Constipation:** when bowel movements are too small, too hard or too difficult to pass on a regular basis compared to normal situations

**CT Scan:** also known as “Computed Tomography”; a medical imaging method obtaining “sliced” images of the body and its structures. Usually takes approximately 15-30 minutes to complete

**Dietitians:** are health care professionals that can give advice on food, nutrition and diet

**ESAS:** “Edmonton Symptom Assessment System” helps identify cancer-related symptoms

**Family Physician (General Practitioner):** a physician who provides primary care to patients, assesses overall health, treats acute and chronic illnesses and refers patients to specialists on an ongoing basis

**Fatigue:** is a feeling of tiredness, or lack of energy

**Impending Fracture:** a bone, such as the hip, with metastases that cause it to be at risk of breaking
**Hormonal Therapy:** drugs that affect the hormones in the body to help control tumour growth

**Hypercalcemia:** when the calcium level in your bloodstream is higher than normal

**Interventional Radiologist:** a radiologist who specializes in minimally invasive procedures with the help of image guidance, such as CT or MRI scans

**Kyphoplasty:** a minimally invasive procedure that uses a balloon to restore the height of the affected vertebra and cement to stabilize the vertebra and provide pain relief

**Medical Oncologist:** a physician who specializes in the treatment of cancer with the use of drugs

**MRI:** “Magnetic Resonance Imaging”; a medical imaging method using magnetic and radio waves to provide detailed pictures of bone and soft tissues found in the body.

**Multiple Myeloma:** a cancer of a type of white blood cell that produces too many abnormal cells which travel through the bloodstream and collect in the bone marrow

**Occupational Therapist:** a health care professional who assists to safely maximize a person’s independence

**Occupational Therapy:** a type of therapy that promotes health and well-being for a person’s everyday living by education or specialized equipment

**Oncology:** The study and treatment of cancer
**Oncologist:** a physician who specializes in cancer care. Some oncologists specialize in radiation therapy (radiation oncologists), chemotherapy (medical oncologist), or surgery (surgical oncologist)

**Opioids:** medications like morphine, hydromorphone, and codeine. There are *long acting* opioids that release the medication slowly and *short acting* opioids that release the medication quickly into your body

**Orthopedic Surgeon:** a surgeon who specializes in musculoskeletal concerns; some examples are fractures or arthritis

**Palliative Care:** provides symptom management, support and comfort to the person and family with a life threatening illness

**Pain Flare:** an intermittent increase in pain. May also be caused by certain therapies, such as radiation therapy

**Percutaneous Vertebroplasty:** a minimally invasive procedure of injecting cement to stabilize the vertebra and provide pain relief

**Photodynamic Therapy:** a treatment method that uses laser light and specialized drugs to destroy tumour cells

**Physiotherapist:** a health care professional who helps with education and rehabilitation of a range of conditions

**Physiotherapy:** therapy that focuses on maintaining, preventing, improving, or restoring physical function and movement

**Primary Cancer:** the site in the body where the cancer first started
Psychologist: a health care professional who assists with providing mental and emotional health care

Psychotherapy: is a means of therapy to help with mental or emotional distress

Radiation Oncologist: a physician who specializes in the treatment of cancer with radiation

Radiation Therapy: a treatment that uses high-energy x-rays to destroy tumour cells

Radiologist: a physician who interprets various imaging, such as x-rays, CT scans and MRI scans

Side effect(s): symptom(s) that may be experienced due to medications or from cancer treatments

Spine: a medical term for bones of the back (also known as "Vertebrae")

Spinal Cord Compression: cancer that has spread to the spine causing pressure on the spinal cord

Stereotactic Body Radiosurgery (SBRS): a treatment where higher doses of radiation are focused on the tumour to help prevent it from growing

Suppository: a drug delivery method into the vagina or rectum

Surgery: a treatment that can help prevent or fix broken bones

Surgical Oncologist: a surgeon who specializes in the treatment of cancer by removing the tumour from the body
Vertebrae: individual bones that stack up like building blocks to make up the spine

Vertebral Compression Fracture: occurs when weakened vertebra of the spine cracks due to pressure from the weight of the body

X-Ray: a diagnostic image from a highly controlled amount of radiation to the body that shows images of the skeleton
## Appendix I

### EORTC QLQ – BM22

Patients sometimes report that they have the following symptoms or problems. Please indicate the extent to which you have experienced these symptoms or problems during the past week. Please answer by circling the number that best applies to you.

<table>
<thead>
<tr>
<th>During the past week have you had pain in any of the following parts of your body?</th>
<th>Not at All</th>
<th>A Little</th>
<th>Quite a Bit</th>
<th>Very Much</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. in your back?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. in your leg(s) or hip(s)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. in your arm(s) or shoulder(s)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. in your chest or rib(s)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. in your buttock(s)?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>During the past week:</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. Have you had constant pain?</td>
</tr>
<tr>
<td>7. Have you had intermittent pain?</td>
</tr>
<tr>
<td>8. Have you had pain not relieved by pain medications?</td>
</tr>
<tr>
<td>9. Have you had pain while lying down?</td>
</tr>
<tr>
<td>10. Have you had pain while sitting?</td>
</tr>
<tr>
<td>11. Have you had pain when trying to stand up?</td>
</tr>
<tr>
<td>12. Have you had pain while walking?</td>
</tr>
<tr>
<td>13. Have you had pain with activities such as bending or climbing stairs?</td>
</tr>
<tr>
<td>14. Have you had pain with strenuous activity (e.g. exercise, lifting)?</td>
</tr>
<tr>
<td>15. Has pain interfered with your sleeping at night?</td>
</tr>
<tr>
<td>16. Have you had to modify your daily activities because of your illness?</td>
</tr>
<tr>
<td>17. Have you felt isolated from those close to you (e.g. family, friends)?</td>
</tr>
<tr>
<td>18. Have you worried about loss of mobility because of your illness?</td>
</tr>
<tr>
<td>19. Have you worried about becoming dependent on others because of your illness?</td>
</tr>
<tr>
<td>20. Have you worried about your health in the future?</td>
</tr>
<tr>
<td>21. Have you felt hopeful your pain will get better?</td>
</tr>
<tr>
<td>22. Have you felt positive about your health?</td>
</tr>
</tbody>
</table>
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To order more copies of the **Bone Metastases Patient Information Book: Helping You to Help Yourself**, please:

1) **MAIL** the completed form below to:

   Dianne Dilnot (Department of Nursing)
   Sunnybrook Health Sciences Centre
   Odette Cancer Centre
   2075 Bayview Avenue
   Toronto, ON
   M4N 3M5

2) **FAX** the completed form below to:

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   Attn: Dianne Dilnot

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