



# OSTEOPOROSIS

NATIONAL ACTION PLAN 2016

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# EXECUTIVE SUMMARY

In 2016 in Australia a bone will be broken every 3.4 minutes due to poor bone health. Osteoporosis affects men as well as women – 30% of these fractures will occur in men. Two-thirds of Australians over 50 have poor bone health and in 2016 this will cost the Australian economy more than \$2 billion in direct costs alone.

Unless action is taken now, things can only get worse. By 2022 there will be 6.2 million Australians aged 50 years or older with osteoporosis or poor bone health – a 31% increase since 2012. The total cost of osteoporosis, poor bone health and fractures over the decade from 2012 to 2022 is expected to be \$33.6 billion.

It does not have to be this way. We know a great deal about osteoporosis and how to prevent it and treat it, but this knowledge is not being translated into practice. We need a significant shift in the levels of public awareness of the causes and consequences of osteoporosis. We need to work together – the public, patients and their carers, GPs and health providers, state and federal governments, and private health insurers – to close the osteoporosis evidence–treatment gap.

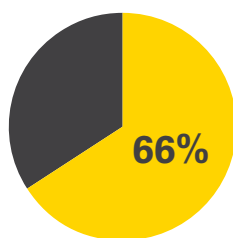
In 2016 a group of stakeholders came together to develop a National Action Plan to establish osteoporosis as a National Health Priority in its own right, along with the necessary focus and funds to combat the growing epidemic of bone disease. The Osteoporosis National Action Plan points the way to broadening the awareness of the importance of bone health, improving the bone health of the Australian population and the outcomes for people with osteoporosis – and to closing the gap.

## 1. Increasing Awareness & Support

Australians need to better understand the causes and consequences of osteoporosis and that it is not simply part of the ageing process. Osteoporosis leads to considerable disability and loss of independence – and it can be fatal. Australians need to have a clearer idea of what to do to improve bone health throughout our lives and what services to access when we need help. Specifically, we need to:

- Establish osteoporosis as a National Health Priority in its own right. Although osteoporosis has been part of the Musculoskeletal National Health Priority since 2002, this has not resulted in significant benefits to the bone health of Australians.
- Deliver consistent health messages about osteoporosis to children and adults alike – the benefits of good diet, alcohol reduction, smoking cessation and regular physical activity.
- Establish a greater emphasis on osteoporosis in the initial and ongoing training of GPs, specialists and allied health professionals and supply them with the tools to aid in risk assessment, early diagnosis and treatment.
- Assist GPs to be able to treat osteoporosis in the context of comorbidities and ageing, to address issues around long-term treatment adherence and side effects, and to provide reassurance to patients about the safety of treatment.
- Provide effective support for Australians suffering from osteoporosis and their carers.

## Australians over 50 who currently have osteoporosis and osteopenia



**4.74  
million**

**AUSTRALIANS OVER 50  
WITH POOR BONE HEALTH**

## 2. Improving Osteoporosis Prevention & Treatment

In Australia, osteoporosis is under-diagnosed and under-treated with as many as 80% of postmenopausal women and 90% of men failing to receive appropriate treatment, despite having presented with a fragility fracture. To close the knowledge–practice gap we recommend:

- The inclusion of fracture risk assessment (including the use of a standardised and accredited fracture risk calculator) in the proposed integrated health assessment checks;
- The expansion of criteria for men and women, from 50 years of age, to access subsidised DXA scans to include additional comorbidities, such as diabetes mellitus, HIV and bone disease related to cancer and its treatment;
- Improved access to subsidised medication, physiotherapy and exercise programs;
- Better support strategies for those with osteoporosis and those who have suffered a fracture, including the ability to access a coordinated Fracture Liaison Service to assess, inform and maintain contact with people on treatment;
- Better information and support to people with osteoporosis and their carers to enable them to self-manage their condition in partnership with primary care providers, allied health professionals and the hospital system. This includes education on treatments that reduce the risk of fracture and could improve survival, and the importance of persisting with long-term treatment;
- For those in high-risk groups, a Medicare-covered dental check-up should be offered prior to commencing treatment to prevent osteoporosis;
- A coordinated strategy to talk to state and federal government and the private health insurance industry to increase support for streamlined and reimbursed diagnostic tests and treatments.

### 3. Finding a Cure for Osteoporosis

Australia is a world leader in osteoporosis and musculoskeletal research, and Australian researchers are in an unprecedented position to take advantage of the latest developments in genomics research and personalised medicine that can more rapidly deliver new treatments to prevent the onset of osteoporosis and improve the lives of Australians living with the disease. Yet our research is poorly supported and our discoveries are not being translated into therapies which could make an important difference to people with osteoporosis.

- We need to develop a unified approach to research.
- To cure osteoporosis, we need to utilise the latest research to remodel bone, to prevent fractures and to develop new drugs that actually build new bone and improve bone quality. Drugs to treat osteoporosis are able to prevent further deterioration of the skeleton, but these drugs do not replace lost bone.
- We need to further develop tools to evaluate new bone-building drugs and identify those who will benefit from the latest genomics approaches.

- We need to foster partnerships between researchers to discover how osteoporosis links with other illnesses; between researchers and the pharmaceutical industrial industry to test new and pre-existing drugs; and between researchers, professional bodies and consumer organisations to mobilise the wider community to take up these new drugs to protect Australians from osteoporosis.

Finally, we need to develop a funding stream to ensure the future of research that will cure osteoporosis.

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Given what we already know, the suffering and human and financial burden of osteoporosis is largely avoidable. The financial costs of implementing the Osteoporosis Action Plan 2016 and getting Australia's bone health on track would be far outweighed by the benefits to the millions of Australians facing a future with osteoporosis. We must begin with the recognition that osteoporosis is a National Health Priority.



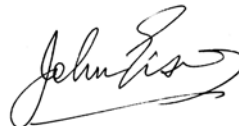
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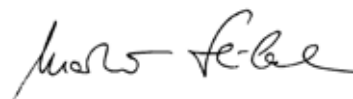
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# INTRODUCTION

We are accustomed to the idea that our bones are durable – they can last for thousands of years in the right conditions. Our bones don't really come to our attention until they break. We think bones are tough, when we think of them at all.

This general idea we have about the durability of our bones is an obstacle to our understanding the realities of bone health in the second decade of the 21st century. We are living longer, but our bones may not always be up to the task of carrying us for our extended lives.

It is estimated that worldwide an osteoporotic fracture occurs every three seconds. From 50 years of age, one in three women and one in five men will suffer a fracture in their remaining lifetime. For women, the risk of hip fracture is higher than the risk of breast, ovarian and uterine cancer combined. For men, the risk is higher than the risk for prostate cancer.<sup>1</sup>

Approximately 50% of people with one osteoporotic fracture will have another, with the risk of new fractures rising exponentially with each fracture.<sup>2</sup> Importantly, fractures are not simply a matter of a break in the bone that will repair over time: fractures can be fatal. Aside from the pain and disability caused by fractures, all fragility fractures are associated with premature mortality in both women and men,<sup>3</sup> and some 20% of people who have a hip fracture will die within six months.<sup>4</sup>

An ageing population also means that more and more people will be living with the long-term consequences of cancers, such as breast cancer and prostate cancer, making these cancers effectively chronic diseases. Important and life-saving chemotherapy, hormone therapy and radiation therapy for these cancers can, unfortunately, also weaken bone, leading to severe osteoporosis which can be life-threatening in turn. In a further important complication, when breast or prostate cancer is advanced it often spreads (metastasises) to the bones. This cancer in the bone can cause severe pain, osteoporosis, fractures and nerve compression that can be difficult to treat.<sup>5</sup>

Technology in the form of x-rays (from 1895) has allowed us to see broken bones and the development of bone density testing in the 1960s means that we know if bones

are healthy or fragile. In the 1990s, a group of drugs called bisphosphonates was approved for the treatment of osteoporosis. These drugs had been first been used to treat cancer-related osteoporosis and then advanced breast and prostate cancer that had spread to the bone.

If we know that poor bone health can lead to broken bones and a first, potentially fatal, fracture leads to an increased risk of a subsequent fracture, why are we – patients, doctors and government services alike – still unable to preserve bone health and prevent fractures?

The demographic tsunami of ageing is upon us and is presenting an unprecedented threat to the sustainability of our health-care systems. We know a great deal about osteoporosis and how to treat it, but this knowledge is not being effectively translated into practice. We need a significant shift in the levels of public awareness of the causes, prevalence and consequences of osteoporosis. We need to work together – patients and their carers, GPs and health providers, state and federal governments, and private health insurers, to close the osteoporosis evidence-treatment gap.<sup>6</sup> At the same time, we have only just begun to access the revolutionary possibilities of genomics and personalised medicine. Important cross-disciplinary research is needed to resolve the genetic components of osteoporosis and the consequences to bone of both cancer and cancer treatment.

Osteoporosis is a chronic disease. In Australia, chronic diseases, often the result of the combination of our changing lifestyles and ageing population, are the leading cause of illness and disability and in 2011 accounted for 90% of all deaths. Chronic diseases like osteoporosis have an enormous impact on our lives and our health system – preventing and treating osteoporosis will deliver benefits to the Australian population that far outweigh their costs.<sup>7</sup>



DXA hip analysis showing femoral neck, greater trochanter and femoral shaft. Courtesy Chris Schultz, Nuclear Medicine PET & Bone Densitometry, Royal Adelaide Hospital.

## What is osteoporosis?

Bone is in a perpetual state of remodelling throughout life, with the entire skeleton being replaced every 10 years.<sup>8</sup> Remodelling is where old bone and damaged areas are removed (bone resorption) and replaced by new bone. For the amount of bone in our skeleton (bone mass) to remain constant, the amount of bone being resorbed needs to be equivalent to the amount of bone being formed.

As we age, men and women experience a reduction in hormone levels, leading to an imbalance in this bone rebuilding process and leaving bones thinner and more fragile. This is osteoporosis. Other factors can also impact on bone strength, but the great concern with osteoporosis is the increased risk of fracture. When someone has osteoporosis even a slight bump or fall can lead to a broken bone (a fragility fracture, also known as a 'minimal trauma' fracture).<sup>9</sup> A fragility fracture is one that involves a fall from a standing height or less, or an event that would not normally result in a fracture if the bone was healthy. Osteoporosis has no signs or symptoms until a fracture occurs,<sup>10</sup> but there are well known risk factors or 'red flags' that signal a person is at risk of developing osteoporosis.

## Who is at risk from osteoporosis?

Bone conditions can impact anyone at any age, and men and women are both at risk.<sup>11</sup> The possibility of sustaining a fracture increases exponentially with age, due not only to the progressive decrease in bone mass, but also due to the increased rate of falls among the elderly – and the elderly represent the fastest growing segment of the population. As life expectancy increases for the majority of the world's population, the human and financial costs associated with osteoporotic fractures will also increase dramatically unless preventive action is taken.<sup>12</sup>

While fragility fractures are most common in people over the age of 50 years, they are not an inevitable part of growing old. A healthy lifestyle and bone-protecting treatments – prescribed when a person has been diagnosed with osteoporosis – can more than halve a person's risk of suffering a fragility fracture.<sup>13</sup> The causes of osteoporosis and risk factors are now better understood and we know that healthy behaviours early in life and through adulthood, such as a diet with adequate protein, calcium, optimal vitamin D, and regular progressive weight-bearing exercise, can have a significant effect on bone health in later life.<sup>14</sup> Better treatments can also significantly improve quality of life.

The most common secondary cause of osteoporosis is the long-term use of anti-inflammatory steroid tablets.<sup>15</sup> This type of medication is very widely used and is often prescribed for the treatment of respiratory disease (asthma), musculoskeletal conditions (rheumatoid arthritis), inflammatory bowel disease and skin disease (severe eczema, psoriasis).<sup>16</sup> One in five patients treated with anti-inflammatory steroid tablets has an osteoporotic fracture within the first 12 months of treatment. This proportion increases to 50% after 5–10 years.<sup>17</sup>

While a previous fracture is a very strong signal, other risk factors include a family history of osteoporosis or fractures,



## ANN MCMAHON

At 61, Ann McMahon was recently diagnosed with osteoporosis. When Ann fractured her wrist in 2011 by tripping upstairs at work, she and her GP continued to monitor her bone mineral density. As well as a family history of osteoporosis, Ann has also used steroids long term for chronic asthma since childhood.

Ann and her husband, Angelo, are empty-nesters, with their two adult sons living nearby. Ann has now been retired for nearly two years following a career in TAFE NSW and is generally fit and well.

'My mother had osteoporosis and my husband is concerned for me, as my mother was very fragile towards the end of her life.

'She had led a very active and engaged life and osteoporosis was one of a range of multiple health challenges for her. It affected her mobility and contributed to her loss of confidence and sense of well-being in her final years. It was also a factor in limiting her independence.

'I was very happy with the testing and diagnostic process at Concord Hospital, where I'm being treated. I felt the decision to medicate was not taken lightly and was based on good evidence. Between the BMD, spinal x-ray and blood tests, patient survey and thorough discussion with the medical practitioners, I felt there was no stone left unturned! I also really appreciated the time everyone took to explain what was going on.

'I've just started treatment with Osteovan (zoledronic acid) infusion which I will have every two years, and I've completed some dental surgery to minimise any possible but, as I understand it, rare complications.

'Now that I'm retired, I can spend more time on exercise. I swim one kilometre a few times a week and I walk quite a bit, including with friends in a walking group and I'm really enjoying our walks.

'While this is all new to me, I would like more information on the best kinds of exercise to do. There seems to be conflicting information and it would be good to know what is or isn't going to help.'



## DAVID PARKIN, OAM

At 69 years of age, in 2011, despite being a self-confessed fitness fanatic, AFL legend David Parkin, was diagnosed with osteoporosis in the spine.

'Ironically, I was just running down some stairs below Flinders St Railway Station, when I fractured my eighth thoracic vertebra,' said David.

'The diagnosis of osteoporosis turned my life upside down. Despite surviving prostate cancer in 2008, my health generally had been extremely good, up to that point.'

The former Hawthorn captain and man regarded as Carlton Football Club's 'Coach of the Century' was living with his partner, Gail, and enjoyed an extremely active lifestyle, running a small business, lecturing at Deakin University and working as a media commentator with both ABC Radio and Fox Sports Television.

'At the time, my lack of mobility and the associated pain, certainly reduced my daily effectiveness and efficiency.

'Under the guidance of my specialist, for the next three years I was subjected to zoledronic acid infusions, on top of a specific weight lifting program, and an increased intake of calcium-enriched milk.

'Fortunately, now at the age of nearly 74, my latest scans show a remarkable improvement in my bone density at the spine as a result of the treatment (part of a research study/program), exercise regime, and concentrated calcium intake.

'Due to my early/accurate diagnosis, expert medical guidance, appropriate treatment and support, I continue to live a very normal, active life!

'In the light of how many people of all ages, and both sexes, whose lives are severely debilitated by this disease, we collectively (including Governments) need a concentrated program of both education and research to reverse the current trend.'

Courtesy AFL Media

low vitamin D levels, low intake of calcium, low body weight, physical inactivity, and smoking or excess alcohol consumption. Osteoporosis is also common in people with malabsorption disorders, such as coeliac disease and with certain hormonal disorders, including overactive thyroid, early menopause or low testosterone.<sup>18,19</sup> It is also increasingly common in those with diabetes mellitus. Similarly, hormonal treatments for breast and prostate cancer, antiepileptic drugs<sup>20</sup> and HIV and its treatments can also lead to bone loss.

## How common is osteoporosis?

While osteoporosis is very commonly seen in the Australian primary health care setting, because it is a 'silent' disease with no pain until a fracture takes place, it remains under-diagnosed and under-treated. Many, especially older people, are unaware that they have osteoporosis and are at risk for fragility fractures.<sup>21</sup> It is therefore difficult to determine the true prevalence of the condition and even the Australian Institute of Health and Welfare admits that figures derived solely from 'diagnosed cases' or 'self-reported cases' are likely to underestimate the actual prevalence of the condition.<sup>22</sup>

In response to the 2011–12 National Health Survey, some 652,500 Australians aged 50 years and over (nearly 10%) reported that they had been told by a doctor or nurse that they had osteoporosis or osteopenia (low bone density).<sup>23</sup> The survey showed women were five times more likely to have been told they had osteoporosis – 15% of women over 50 (542,500) and 3% of men (110,000).<sup>24</sup>

In 2013, however, an Osteoporosis Australia report entitled *Osteoporosis costing all Australians: a new burden of disease analysis 2012–2022*, put the number of Australians over 50 with poor bone health at 4.74 million (66%).<sup>25</sup> A separate report estimated that in 2012, 1.2 million Australians were already affected by osteoporosis.<sup>26, 27</sup> Population ageing means the population over 50, those most at risk, is estimated to grow to at least 11.8 million by 2050, with increased associated fractures and health and disability costs.<sup>28</sup>

The early identification of individuals at increased risk for osteoporosis is critical for the opportunities it offers to apply preventive measures that can improve bone health and decrease the risk of fractures in a cost-effective manner.<sup>29, 30, 31</sup>

## The costs and consequences of osteoporosis

Osteoporosis causes painful breaks and fractures leading to reduced mobility, reduced health generally and reduced quality of life. Fractures due to osteoporosis, including at the hip and pelvis, spine, ribs, wrist, forearm and upper arm, and ankle and foot, can result in chronic pain, disability, loss of independence and premature death, especially from hip and spine fractures.<sup>32,33</sup>

Wrist and forearm fractures may affect the ability to write or type, prepare meals, perform personal care tasks like eating, dressing or going to the toilet, or manage household chores. Fractures of the spine and hip can affect mobility, making activities such as walking, climbing stairs, bending, lifting, pulling or pushing difficult. Hip fractures, in particular, often lead to a marked loss of independence and reduced wellbeing.<sup>34</sup>



Hospitalisation for fragility fractures also generates substantial costs to the community. It is estimated that there will be more than 155,000 fractures due to osteoporosis in 2016 alone.<sup>35</sup> In Australia in 2013–14 there were 62,132 hospitalisations for fragility fractures in people aged 50 or over, with women more than 2.5 times more likely to be hospitalised than men.<sup>36</sup> The hospitalisation rate for people with osteoporosis was greatest for people aged 85 or over and higher in females than in males.<sup>37,38</sup> Some 25% of hip fracture patients end up admitted to residential aged-care facilities, with a significant cost to the health system.<sup>39</sup> As the Australian population continues to age, the annual number, and associated burden, of people admitted to hospital with a hip fracture, is expected to increase.<sup>40</sup>

In 2012 Osteoporosis Australia estimated the total direct and indirect costs of osteoporosis/ osteopenia in Australia in 2012 to be \$2.754 billion. Of this total, \$2.589 billion were direct costs, mainly associated with fractures with \$165 million as indirect costs, including productivity losses associated with hospitalisation for fractures.<sup>41,42</sup>

## Osteoporosis – A National Health Priority

In July 2002 the Australian Health Ministers declared arthritis and musculoskeletal conditions, including osteoporosis, as a National Health Priority Area (NHPA). This focus on a disease or condition provides the framework within which interventions to benefit the population are introduced, such as health promotion, diagnosis, treatment or management.

Arthritis and musculoskeletal conditions were selected on the basis that they affected a large proportion of the population; at the time almost one-third of Australians reported these diseases and conditions as long term. They were also the second most common reason for presentation to a general practitioner, and the third leading cause of health expenditure.<sup>43</sup>

Osteoporosis was included as a subset of arthritis and musculoskeletal conditions because of its high prevalence, significant health consequences and high health costs. It was also considered that a large proportion of the population would benefit from intervention.

A National Action Plan (NAP) was developed in 2004 to guide the National Health Priority Action Council (reporting to the Australian Health Ministers) and the Australian Department of Health and Ageing.

The NAP marked for urgent action the need to reduce the burden of disease; advance and disseminate knowledge and understanding of osteoporosis, osteoarthritis and rheumatoid arthritis; reduce disadvantage by considering groups with special needs; drive national improvements in systems and services; and measure and manage performance and outcomes. The focus for osteoporosis was to be on promoting healthy lifestyles and self-management to optimise health outcomes; best practice for optimal management and appropriate post-fracture assessment to minimise further osteoporotic fractures.<sup>44</sup>

The NAP also outlined the need to develop, prioritise and progress a research agenda to support this national health priority, including establishing baselines and implementing ongoing data collection systems.<sup>45</sup>

In 2005 the Australian Health Ministers' Conference endorsed the National Chronic Disease Strategy, which incorporated musculoskeletal diseases and osteoporosis. A National Service Improvement Framework was developed for musculoskeletal diseases, including measures to limit the development and progression of osteoporosis, slow the onset of complications that can cause severe disability, reduce avoidable declines in health, and reduce variations in care by outlining the services that all people should expect to receive from the Australian health system, across the continuum of disease.<sup>46</sup> The intention was to achieve better health outcomes through the provision of equitable, timely and effective care.

After a lengthy hiatus, from 2014 there has been considerably greater activity around chronic diseases generally and specifically in the musculoskeletal area. In 2014, the NSW government's Agency for Clinical Innovation established the Musculoskeletal Primary Health Care Initiative in partnership with three sites at Murrumbidgee, Northern Sydney and the Mid North Coast. This is a two-year trial to plan, implement and evaluate a 'one-stop' program of care within primary care settings for people with a first fracture who need the established model of care for the prevention of subsequent osteoporotic fractures.<sup>47</sup>

In 2015 at the federal level, in the context of other major health reforms, work began to develop a new National Strategic Framework for Chronic Conditions (NSFCC), to replace the National Chronic Disease Strategy (2005). This is to be an overarching policy framework for chronic disease prevention and management in Australia. It is intended that the NSFCC will cater for shared health responsibilities, risk factors, prevention strategies and multimorbidities, and provide a model under which new evidence can be easily incorporated. This work will also provide an opportunity to consider how best to facilitate coordinated, integrated and multidisciplinary care, improve utilisation of primary health care organisations, and recognise patient needs. Specifically, areas of prevention include risk reduction, a partnership model including patients and carers, critical early life stages and timely and appropriate detection. Care and treatment revolve around active engagement to slowing disease progression, helping to prevent and delay the onset of additional chronic conditions, complications and associated disabilities; continuity of care; accessible health services; information sharing; and supportive systems. It is expected that the NSFCC will be published in late 2016.<sup>48</sup>

The Federal Primary Health Care Advisory Group (PHCAG) delivered its *Better Outcomes for People with Chronic and Complex Health Conditions* report in December 2015.<sup>49</sup> The PHCAG report called for changes that were taken up in the Federal Government's *Healthier Medicare* reforms announced on 31 March 2016, aimed at modernising and improving coordination in chronic disease management in Australia. Central to this are the two-year *Health Care Homes* trials to begin in 2017. *Health Care Homes* focus on a coordinated, multidisciplinary approach to achieving patient-centred outcomes. Patients enrol at the 'homebase' medical practice that coordinates, manages and supports their care. Patients, families and carers are partners in the care process, with greater access to care including telephone, email or videoconferencing. Patients select a preferred clinician to deliver flexible, high quality, team-based care. Data collection



## ANNETTE ASIMUS

In early 2014, Annette Asimus was turning to get into the shower when she felt a sudden stabbing pain. X-rays showed that she had five fractures in the spine. She also fractured her ribs turning over for the x-ray, plus she had eight old rib fractures. At 59, Annette was diagnosed with osteoporosis.

'I knew I had osteopenia (thinning bones) and a tendency to fracture for some time. I had fractured ribs coughing with the flu,' said Annette. In 2004 she had been diagnosed with an underactive thyroid and rheumatoid arthritis, both of which can increase the risk of osteoporosis.

Annette began treatment for osteoporosis, starting in 2014. She has an Aclasta (zoledronic acid) infusion once a year in February, which takes about an hour, and takes high levels of vitamin D and calcium. This will hopefully prevent further deterioration of her bones and more fractures.

Annette retired in February 2016 and lives with one of her two adult sons. She has lived all her life in Dubbo and at the time of her back fractures was working at the Mitre 10 hardware shop.

With her multiple chronic conditions, Annette has to pace herself. 'I have good days and bad days, but I have permanent pain and need to take strong painkillers throughout the day.

'I really feel that GPs and other medical staff, like x-ray staff, need to be more aware of osteoporosis and what it's like and how to help people.

'There also needs to be more understanding about how depressing it is to live with the chronic pain that osteoporosis gives you. You don't want to be around people or go anywhere, because it's too much effort and you can't enjoy it.'

Annette is determined not to let her pain take over her life, however. 'I find that if I have something else to focus on, the pain doesn't bother me as much and I'm going to join the local Pink Angels charity for breast cancer. Thinking about other people helps me to not think about my own problems.

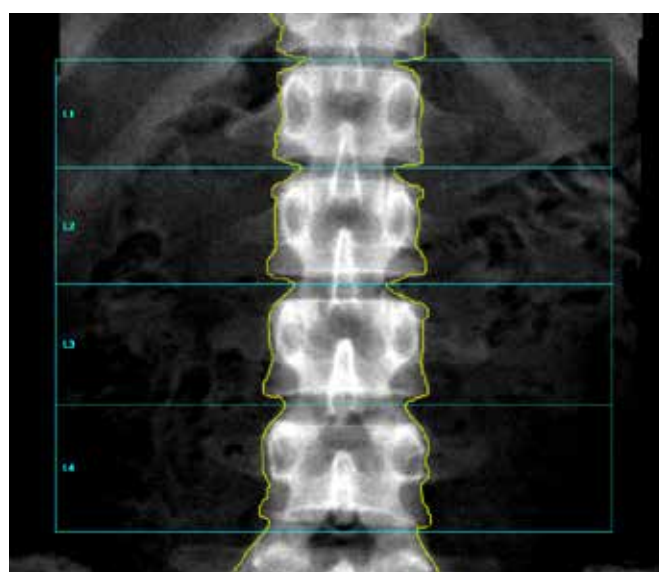
'I've been active all my life, but like anyone with osteoporosis I worry about what my life will become and that I'll end up in a wheelchair.'

and sharing are important aspects of the *Health Care Homes* initiative.<sup>50</sup>

In late December 2015 the Federal Health Minister, the Hon Sussan Ley, announced the establishment of 31 Primary Health Networks, with the first at Northern Sydney (which already has a musculoskeletal component and now incorporates a focus on falls).

In May 2016 the Federal Parliamentary *Inquiry into Chronic Disease Prevention and Management in Primary Health Care* reported that chronic conditions, including cancer, and comorbidities were increasing with age and that there was a consequent need for greater planning and coordination and a resolution of federal/state health funding issues. Recognising that the majority of chronic diseases are caused by lifestyle – smoking, alcohol, inactivity and poor nutrition – there was a focus on prevention and a call for widening the scope of screening and health checks to identify the earliest signs of chronic disease, including integrated health assessments covering the major conditions. The Inquiry called for an expanded role for nurses and potentially for private health insurance companies, along with their programs for prevention and maintenance. As with the NFSCC draft and the PHCAG *Better Outcomes for People with Chronic and Complex Health Conditions* report, there was an emphasis on partnering with patients and carers and the need to increase health literacy. The report was concerned about access, especially for disadvantaged groups including rural and Aboriginal and Torres Strait Islanders. It also considered eHealth and the accessibility of medical records as vital in the care of people with chronic conditions.<sup>51</sup>

Considerable change is under way through ongoing national reforms to deliver a more sustainable, coordinated person-centred health system that is focused on chronic health conditions, such as osteoporosis. There is also a welcome emphasis on the need for early detection and timely treatment. In addition, new osteoporosis guidelines for GPs are in train and a new Hip Fracture Care Clinical Care Standard was released in September 2016.



DXA lumbar spine analysis showing regions L1-L4. Courtesy Chris Schultz, Nuclear Medicine PET & Bone Densitometry, Royal Adelaide Hospital.

## Closing the knowledge-treatment gap

While it is certainly encouraging to see government recognition of the burden of chronic disease on Australians and the Australian economy, it is a concern that osteoporosis itself, despite its attendant disability and mortality, remains a largely hidden subset of 'musculoskeletal diseases'. The opportunities created by the idea of an integrated health assessment, which includes tests for cardiovascular, kidney disease risk and diabetes<sup>52</sup> are missed by the lack of a fracture risk assessment.

It is important to also remember that despite musculoskeletal diseases being an Australian National Health Priority for 14 years, osteoporosis remains an under-diagnosed and under-treated disorder<sup>53</sup> with around 80% of people with fractures receiving no follow-up treatment.<sup>54</sup> There has been little improvement for the growing numbers of osteoporosis sufferers and the link with effective and well-tolerated treatments, and modifiable lifestyle activities is still not being clearly made to the general public. In 2006 the Australian Bureau of Statistics found that almost 60% of adult Australians have low health literacy, which means they are not able to effectively exercise 'choice or voice' when making health care decisions.<sup>55</sup> In 2015 a Garvan Research Foundation survey showed that 60% of Australians have a limited understanding of osteoporosis, with one in ten misunderstanding what the disease is, demonstrating a disconnect between awareness and understanding of osteoporosis.<sup>56</sup>

While laudable efforts have been made to properly manage osteoporosis in primary care and in the hospital system, there remains a disconnect between fracture repair in hospitals and assessment and management of the underlying disease in hospital, rehabilitation or in primary care.

Osteoporosis research has led to vast improvements in our understanding of the causes of the disease, our ability to diagnose it with the use of fracture risk calculators and DXA scans, and to treat it with new pharmaceuticals that maintain or increase bone density. However too little has been done to close the knowledge-practice gap. Health care professionals still receive inadequate training about bone health and public education programs have not been noticeably successful, nor have they worked to integrate messages about bone health with broader messages about the importance of healthy lifestyles in preventing an array of chronic disease problems.<sup>57, 58</sup> There has also been a lack of engagement with children who are at the most beneficial time for building stronger bones to complement their greater longevity.

To overcome these obstacles to closing the knowledge-practice gap, osteoporosis needs to be a National Health Priority in its own right. A systems-based approach including: raising awareness in the general public; encouraging working partnerships of patients and their families and carers, general practitioners and allied health professionals; improved rebated and nationwide access to DXA scans and preventative treatment; and increased numbers of fracture liaison services; is needed to address the growing public health problem posed by osteoporosis.<sup>59</sup>



# 1. AWARENESS & SUPPORT

Australians need to better understand the causes and consequences of osteoporosis – that it is not simply part of the ageing process and that it can lead to considerable disability. It can even be fatal. We also need to have a clearer idea of what we can do to improve our bone health throughout our lives and what services to access when we need help.



## RECOMMENDATION 1

Establish osteoporosis as a National Health Priority in its own right.

## RECOMMENDATION 2

Better coordination and targeting of clear, consistent, evidence-based information to:

- a. enable people to minimise the risks for osteoporosis, with guidelines on the benefits of good diet with fruit and vegetables, low salt, vitamin D, protein, calcium and exercise. This should be part of a collaborative development of consistent health messages across the range of health conditions including osteoporosis, cardiovascular health, obesity and mental health to highlight the benefits of good diet, alcohol reduction, smoking cessation and regular physical activity for all these conditions. There should be specific information for expectant mothers and children at the time when their bones are forming.
- b. enable people to assess their risk of a fracture, with supporting recommendations. This should include the development of a validated online fracture risk calculator that is easy to use. The results can be used to start a conversation with their health provider.
- c. increase their understanding of the significance of osteoporosis in their daily lives, and specifically that following a first fracture, there is a greater risk of sustaining another fracture, especially in the first 12 months.<sup>66, 67, 68</sup>
- d. address misconceptions around treatment with bisphosphonate drugs (to prevent bone deterioration), including the effectiveness and safety of treatment, and the very low risks of osteonecrosis of the jaw (ONJ) and atypical femur fracture, to enable consumers to make an informed decision about the use of preventative medication.
- e. increase awareness of programs and services for people with osteoporosis.

ONJ is a very rare (1 person in 100,000 receiving anti-osteoporosis treatment) but serious condition where the jaw is damaged. Since 2001 very rare cases of ONJ have been reported, mainly in cancer patients receiving high-dose intravenous bisphosphonate treatment, following an infection related to dental surgery. The doses of bisphosphonates for osteoporosis are much lower. While there have been guidelines overseas on safe dental treatments for patients on bisphosphonates since 2006,<sup>60</sup> there does not appear to be a consensus on such dental treatment in Australia. When used for patients at high risk of fracture, however, the balance of benefit to harm still favours the use of bisphosphonates.<sup>61</sup>

Although the risk is very low, as osteoporosis requires long-term treatment, high-risk patients, including those with other chronic conditions,<sup>62</sup> should be advised to have a dental check-up and if possible to complete any necessary major dental work prior to beginning treatment.<sup>63</sup>

Atypical femoral fractures are an uncommon type of fracture that occurs with little or no trauma and that have been linked to bisphosphonate treatment. Again, the overall benefit in preventing hip fractures greatly exceeds the risks of causing an atypical femur fracture.

Intravenous or oral bisphosphonate therapy should be evaluated to determine if the benefits of continuing therapy still outweigh the potential risks.<sup>64, 65</sup>

### RECOMMENDATION 3

Develop effective self-management resources that provide people with osteoporosis (and their carers) with information and skills to enhance their ability to take an active role in their own health care, especially before a fracture occurs, when appropriate diet, safe and effective exercise and adherence to bisphosphonate and other effective and well-tolerated therapy could reduce the likelihood of fracture. Self-management resources should include the ability to access a coordinated network of professionals for further information or treatment.<sup>69</sup>

### RECOMMENDATION 4

Develop School Education Programs on the importance of a healthy skeleton within the national school curricula, integrated with general health information on the links between risk factors and comorbidities with other chronic conditions.

Given that 90% of peak bone mass is acquired by age 18 years for girls and by age 20 years for boys, targeting adolescents before and during puberty could have a considerable impact on increasing peak bone mineral mass and maintenance of bone health, potentially delaying the onset of osteoporosis and decreasing the risk of fractures later in life.<sup>70</sup>

This can include an emphasis on weight-bearing exercise and diet, especially calcium and protein intake, the need for vitamin D and the avoidance of risky behaviour in smoking and alcohol consumption. Exercise could be integrated with existing campaigns such as the 'Girls make your move' or 'Sporting Schools' campaigns.<sup>71, 72</sup>

### RECOMMENDATION 5

Expand the competencies on musculoskeletal health in the education of medical trainees, especially those looking to specialise in rheumatology, endocrinology, gynaecology, geriatrics, rehabilitation and orthopaedics, along with allied health professionals and nurses.



#### ANNAROSA

Published author, wife and keen walker, Annarosa, 54, has always been aware of the importance of looking after her health. However, in September 2010, while walking very early one Sunday morning, Annarosa tripped over her bootlaces, landing heavily on her wrist.

'I thought, "Oh gosh, this hurts," but I never suspected I had broken anything,' said Annarosa.

With severe and increasing pain, Annarosa went to the emergency department at Sydney's Royal Prince Alfred Hospital, where an X-ray confirmed she had fractured her wrist.

'The doctors kept asking me how I had fallen and how the fracture had occurred. They explained that when you fall from your own height, you shouldn't break a bone.

'After the swelling subsided, I returned to have my wrist set in a cast and to undergo a bone mineral density scan.'

Annarosa was diagnosed with osteoporosis and was asked about her family history of the disease. She had a grandmother on one side, and a grandmother's sister on the other side of her family with osteoporosis.

'I was really surprised and a bit upset – I was only 48 at the time, and had not considered that osteoporosis was a disease that people of my age developed. Fortunately, it was caught early, and I was able to commence treatment and to care for, and improve the strength of my bones, to minimise the potential for further fractures.

'I've been very impressed with the way in which the public health system has kept tabs on me and ensured that my treatment is monitored and adjusted. I feel that I have been looked after extremely well, and the strength and density of my bones has actually improved and I've had no further fractures.'

Annarosa is now being treated with anti-osteoporosis medication and takes a combination of calcium and vitamin D supplements to support her medication regimen. As a vegan, she tries to consume sufficient calcium and vegetable protein to aid her bone health, and works hard to avoid tripping or unnecessarily injuring herself.

## RECOMMENDATION 6

Further develop GP engagement programs to:

- a. enable them to identify patients at risk, including men, and then have them investigated and treated for osteoporosis. This includes the need for a clinically proven, government certified fracture risk calculator developed for the Australian context. There is an urgent need for updated GP guidelines to address the diagnosis and treatment of osteoporosis.
- b. address osteoporosis in the context of comorbidities and ageing. The management of people with multimorbidities 'requires greater planning and coordination by GPs and their teams'<sup>73</sup> as 'management of one disease can often contribute to poorer outcomes of a co-existing disease'.<sup>74</sup> There is an urgent need for GP guidelines to address the management of osteoporosis in patients with multimorbidities and the complexity of clinical decision-making in these patients. GPs should be encouraged to follow-up patients to monitor the use of medications that increase the risk of falls and/or fracture.<sup>75</sup>
- c. highlight their role in prevention and treatment.
- d. address challenges around long-term treatment adherence and minimising side effects.
- e. provide reassurance to patients about the safety of treatment.

## RECOMMENDATION 7

Develop accredited 'Continuing Medical Education' programs, in partnership with professional bodies, to assist in educating health care professionals (GPs, radiographers, nurses, exercise physiologists, pharmacists, physiotherapists, occupational therapists, etc) on the issues of bone fragility.

## RECOMMENDATION 8

Develop a research program that includes:

- How clinical research translates into the community setting, including how people respond to treatment modalities, the types of medication they take and the degree to which they adhere to treatment, the factors that motivate people to seek help and treatment and the obstacles that prevent them from presenting for treatment, and the effects that treatment has on patients' quality of life.
- Why are most education-based programmes for GPs ineffective? New education tools and resources should be implemented and assessed.
- Evaluation of which awareness-raising strategies promote behaviour change; how widespread that change is; and whether any improvement is seen in the bone health status of target audiences.
- How messages of bone health might be incorporated in general health awareness programs used for other chronic diseases. What can be learned from what has been done and what has worked in other chronic disease prevention programs? What successful social marketing campaigns for specific diseases (such as diabetes, breast cancer, substance use, HIV/AIDS, and issues such as traffic safety) or for specific populations (eg youth, or men) can serve as models for the field of bone health?<sup>76</sup>
- The feasibility and impact of population-based strategies.<sup>77</sup>



## 2. PREVENTION & TREATMENT

Osteoporosis remains under-diagnosed and under-treated in Australian primary care, with as many as 80% of postmenopausal women and 90% of men going untreated despite having presented with a fragility fracture.<sup>78, 79</sup> In the Australian BoneCare study of more than 88,000 postmenopausal Australian women attending primary care physicians, 29% reported at least one low-trauma fracture after menopause. However, less than one-third of these women were on specific treatment for osteoporosis, and only 40% were ever told they had osteoporosis.<sup>80</sup> This represents an example of the gap between evidence and clinical practice.<sup>81</sup>



### RECOMMENDATION 9

Remove obstacles to closing the knowledge–practice gap in primary care to:

- a. improve the recognition and assessment of risk (including previous fracture),
- b. include fracture risk assessment in the proposed integrated health assessment checks,
- c. expand criteria for access to subsidised DXA scans to include diabetes mellitus, systemic lupus erythematosus, HIV and its treatment, and cancer-related bone disease, for men and women from 50 years of age,
- d. empower GPs to give appropriate treatment and advice,
- e. improve access to Medicare-subsidised medication to treat osteoporosis, physiotherapy and exercise programs.

The reasons for the under-diagnosis of osteoporosis and even lower rates of treatment are complex. A primary reason is that many physicians (and people themselves) do not recognise a first fracture as osteoporotic and so fail to initiate investigation or treatment for osteoporosis. A first fragility fracture should be the trigger for assessing, treating and offering lifestyle advice to reduce a person's risk of further broken bones.<sup>88</sup>

Other reasons can be a general lack of awareness of osteoporosis by both the patient and the doctor, or the low priority of osteoporosis in the competition with other comorbidities, particularly in the elderly.

There are also confusing messages about osteoporosis and its treatment, ie that 'osteoporosis is not a disease, it's just about ageing', or that treatments don't work or have severe side effects, etc. In some locations, particularly in regional and rural Australia, diagnosis and treatment are affected by limited access to specialist services, including DXA scanning.

## DIAGNOSIS AND TREATMENT OF OSTEOPOROSIS

Diagnostic assessment for osteoporosis should consist of a thorough medical history, clinical examination, a fracture risk assessment including using a validated fracture risk calculator such as FRAX<sup>®</sup>,<sup>82</sup> Monash Osteoporosis Risk Score (MORS),<sup>83</sup> or the Garvan-developed calculator.<sup>84</sup> At the predefined set of risk factors for each calculator, women older than 50 years and men older than 70 years should be followed up by a subsidised measurement of bone mineral density (BMD) by Dual X-ray Absorptiometry (DXA scan) at spine and hip and, if applicable, laboratory tests and radiographs of the thoracic and lumbar spine.<sup>85</sup>

Major clinical risk factors are age, sex, previous fragility fracture, particularly of the hip, wrist and spine and falls history. Increased risk is indicated by low body mass index (less than 19kg/m<sup>2</sup>), family history, current glucocorticoid (anti-inflammatory steroid) treatment, current smoking and alcohol intake of three or more units daily.<sup>86</sup> Secondary risk factors include rheumatoid arthritis, hormone imbalances (including those caused by cancer treatment), prolonged immobility, organ transplantation, diabetes mellitus, hyperthyroidism, gastrointestinal disease, chronic liver or kidney disease, chronic obstructive pulmonary disease, epilepsy, systemic lupus erythematosus or HIV.<sup>87</sup>

If the patient is confirmed to have osteoporosis by DXA scan showing low bone density, then anti-osteoporosis drug treatment should be offered.<sup>89</sup> Anti-osteoporotic medication is recommended for patients with a fragility fracture, for those aged 70 years or over with a low bone density on DXA scan, or for those who are currently taking prolonged high-dose corticosteroids.<sup>90</sup>

Therapy can also be commenced in patients with prevalent vertebral fractures or non-vertebral fragility fractures without a DXA scan if this is felt to be inappropriate or impractical.<sup>91</sup> Having a low bone density, however, is only one of a number of risk factors for fragility fractures.<sup>92</sup>

For those with osteoporosis, management strategies incorporate bone-strengthening lifestyle choices, as well as the use of medications, such as oral or intravenous bisphosphonates or denosumab, that can help maintain or improve bone density<sup>93</sup> and reduce the risk of both spinal and non-vertebral fractures. Despite high-level evidence for effectiveness, safety and cost effectiveness, less than 30% of Australian women and even fewer Australian men with osteoporosis (even those with fragility fractures) are being managed appropriately.<sup>94</sup>



Systematic approaches using either fracture risk calculators such as FRAX, MORS, or the Garvan fracture risk calculator, and multidisciplinary approaches, including family doctor liaison, have improved rates of treatment, but greatly increased levels of both diagnosis and treatment of osteoporosis, with multifaceted and systems-based approaches, such as inclusion of fracture risk in the proposed integrated health assessments, are still needed.<sup>95, 96</sup>

One issue specific to densitometry screening may be the lack of Medicare reimbursement for bone densitometry scans for some patients, and gap fees. The range of rebatable scans and treatment should be expanded to include men and women from 50 years of age with diabetes mellitus, epilepsy, systemic lupus erythematosus, HIV or cancer-related bone disease.

In general, advice also needs to be provided to help people address their modifiable risk factors (diet, exercise, smoking, alcohol), as part of both the treatment and prevention of osteoporosis.<sup>97</sup> General practitioners should provide postmenopausal women and older men at risk of, or diagnosed with osteoporosis, with access to education, psychosocial support and encouragement to seek support from appropriate sources according to individual needs.<sup>98</sup>



## JENNY TRACY

Jenny Tracy was only 27 years old when she was diagnosed with osteopaenia (low bone density) following a car accident which left her with a fractured C1 vertebra. She was working as a paediatric nurse in the local hospital at Dubbo.

That was in 1988 and since then Jenny has become a mother to Zoe (8 years old) and Angus (5 years old). 'I work three days a week and run a small farm, so life's pretty hectic', said Jenny.

Until her accident, Jenny had been in good health, growing out of her childhood asthma and epilepsy.

'Both my 75-year-old mum and 48-year-old sister have osteoporosis and receive treatment for it. My sister also has had a fractured neck of femur requiring surgery at age 45.'

'I consider myself pretty fit and healthy. I ride horses and compete on a monthly basis. I do take calcium tablets daily as I'm a little nervous that a fracture isn't far away. I have had no other treatment.

'I have been to see various doctors and specialists about osteoporosis, but never got clear information about how I should be treated, which I found really frustrating. This why I don't take anything.

'Comments I received were "It's up to you if you want treatment, you haven't had a real fracture so you don't have osteoporosis. Just because your mum and sister have it doesn't mean you'll get it ...".

'No-one really seems to know how to treat young osteopaenic patients. I breast fed both my children and was told I should stop breastfeeding when my baby was 8 months old because of my osteopaenia. I continued to feed him till he weaned himself at 13 months old. Once again, I couldn't get a clear answer on the effects of breastfeeding.'

'I would like to see someone who is confident in giving advice and treating early onset osteoporosis.'



## RECOMMENDATION 10

Drive the implementation and funding of Fracture Liaison Services (FLS) in the hospital and primary healthcare setting to prevent further fractures, including engaging with the Department of Veteran Affairs and Primary Health Networks.

Individuals who have suffered a first fragility fracture are at considerably increased risk of second and subsequent fractures. In the absence of a systematic approach to delivery of secondary fracture prevention, the vast majority of fragility fracture patients do not receive the osteoporosis care that they need.<sup>99, 100</sup> Anyone who has experienced a fragility fracture should be managed within a formal integrated system of care that incorporates a Fracture Liaison Service, also known as a Secondary Fracture Prevention Program.<sup>101, 102, 103</sup>



## RECOMMENDATION 11

Better coordination and targeting of the information and support provided to people with osteoporosis and their carers, including:

- a. education on treatments that reduce the risk of fracture and could improve survival, particularly in those groups with the highest risk of fracture (subsequent fracture prevention).
- b. the importance of persisting with long-term treatment (education of benefits of treatment versus potential side effects).
- c. a Medicare-covered dental check-up prior to treatment with oral bisphosphonates for high-risk groups (those with other chronic conditions, or people on cancer treatment, etc),<sup>115</sup> along with the treatment of any major dental problems (ie those involving surgery). As treatment with oral bisphosphonates is lengthy – 3-5 years – and there is a continued reluctance among the dental profession to perform dental surgery on people being treated with these drugs, in the interests of equity of access, it is important that high-risk groups are able to assess and meet their dental needs prior to commencing treatment.
- d. support strategies, including accessing a coordinated Fracture Liaison Service, to assess, inform and maintain contact with people on treatment (offering personalised support strategies and comprehensive helpline); engagement of Medicare and health insurance companies; consumer stakeholder forums and peer support groups; and a better understanding of available services and best practice treatment.

## FRACTURE LIAISON SERVICES

Fracture Liaison Services (FLS) place a fracture coordinator at their centre and can result in fewer fractures, improvement in the quality of life of patients and cost savings for the health system.<sup>104, 105, 106</sup> FLS have been demonstrated to provide clinically effective care in a highly cost-effective manner in a growing number of countries throughout the world.<sup>107, 108, 109, 110</sup>

The first Facility Level Audit undertaken in 2013 of 116 public hospitals in Australia and New Zealand providing operative intervention for hip fracture, showed that 54% of hospitals provided some form of orthogeriatric care for older orthopaedic patients ranging from a true shared-care model to a consultation-based approach to care. In the 2015 Audit, 68% (81/120) of reporting hospitals had a formal orthogeriatric service in place for people with a hip fracture.<sup>111</sup> Availability of dedicated FLS to cover all types of fragility fractures and not just in the older population, however, remains limited. In 2015, 21% reported access to an FLS, compared with 15% reported in 2013.<sup>112</sup> Osteoporosis clinics were available in 40% of hospitals in 2015, compared with 35% in 2013. Combined falls and bone health clinics were available in 18% of hospitals in 2015, only slightly up from 16% in 2013.<sup>113</sup> Of those hospitals that reported plans to alter services in 2016, 69% identified barriers to proposed hip fracture service redesign, with funding being the primary barrier, followed by staffing levels, and the politics or culture of the environment.<sup>114</sup>

The 2015 draft *Hip Fracture Care Clinical Care Standard* recommends that a patient presenting to hospital with a suspected hip fracture receives care guided by timely assessment and management of medical conditions, including diagnostic imaging, pain assessment and cognitive assessment.<sup>116</sup> Before a patient with a hip fracture leaves hospital, they should be offered a falls and bone health assessment, and a management plan based on this assessment to reduce the risk of another fracture. The patient and their carer should be involved in the development of an individualised care plan for when the patient leaves hospital. The plan includes a summary of any changes in medicines, any new medicines, mobilisation, wound care and function post-injury, recommendations for future fracture prevention and referral to ongoing rehabilitation if clinically indicated. This plan is provided to the patient before discharge and to their general practitioner or ongoing clinical provider within 48 hours of discharge.<sup>117</sup>

All individuals with fracture should be fully assessed for fall risk factors and appropriate interventions to reduce falls should be undertaken.<sup>118</sup> Reviewers of the Facility Level Audit felt that the UK NHS NICE Guidelines offered high quality, current and directly applicable recommendations<sup>119</sup> including continued, coordinated, orthogeriatric and multidisciplinary review and discharge planning liaison or integration with related services, including falls prevention, subsequent fracture prevention, mental health, cultural services, primary care, community support services and carer support services.<sup>120</sup>

## HIP FRACTURES AND FALLS

Every day, more than 40 Australians will break a hip. Most are aged 65 years or over, and more than half are aged 85 years or over. Virtually all of these people will be admitted to hospital, and most will have some kind of surgery. Two people will die in the hospital, and at least four will need to go into a residential aged-care facility, either while they recover, or permanently. A year later, less than half of those original 40 people will be able to walk as well as they did before the fracture, and another six or seven will have died.<sup>121</sup> These fractures can be a source of ongoing pain and disability and are a considerable burden to the community and the Australian health system.<sup>122</sup>

Around 19,000 Australians over the age of 50 years were hospitalised with a hip fracture in 2013–14.<sup>123</sup> Aboriginal and Torres Strait Islander Australians were much more likely than other Australians to be hospitalised for an osteoporotic hip fracture. They were also on average much younger at the time of their fracture.

Most osteoporotic hip fractures result from a fall<sup>124</sup> related to other aspects of ageing including problems with vision, muscle weakness, poor balance, cognitive impairment, a history and/or fear of falling, and the use of medications causing drowsiness or confusion. Extrinsic risk factors include tripping hazards (such as uneven ground, loose rugs or clutter), wet or slippery surfaces, slippery footwear, poor lighting and lack of handrails on stairs. However the weaker the bones, the more likely they are to fracture in a fall. The key strategy is a combined falls and fracture prevention plan, including the prevention and management of osteoporosis.<sup>125</sup>



### GWENDA GAUDRY

In 2007 Gwenda Gaudry had surgery to remove her thyroid and at the time was diagnosed with osteoporosis. 'I was 59, living with my partner Jim, and working 20 hours per week,' said Gwenda.

Until this point, Gwenda's health was good and she had had no fractures. Two of Gwenda's sisters also have osteoporosis.

'I started taking Fosamax (alendronate) from 2007 through to 2012, but I began having chest pains, so I was swapped to Actonel (risedronate).

'I had a fall in March 2014 and fractured my pelvic bone and some ribs. I fractured my hip in January 2016.'

In February 2016, Gwenda ceased taking Actonel and had her first Prolia (denosumab) injection. 'I have tolerated both Actonel and Prolia well, with no side-effects.'

'Since my hip fracture I have had wonderful care and follow-up treatment from Nepean Hospital and their ancillary services. In my case, the services have been great.

'It has been quite a struggle with the pain, but I can see myself slowly improving. I do worry that I may not make a full recovery and I feel self-conscious about my 'slowness of movement' when with company. I don't like it that some of my independence has been reduced.

'I am continuing to work hard at my recovery doing physio and hydro a couple of times a week, but this hip fracture has resulted in me stopping work and led to an earlier than expected retirement.

'I think better awareness and education will help a lot. With better awareness people around and close to me will better understand what I'm dealing with. Keeping your calcium and vitamin D levels up throughout your life is so important.'

## RECOMMENDATION 12

Extend engagement to all health care providers to ensure a real understanding of osteoporosis patients and the support needed for carers and families (eg opportunity to re-engage with dentists, the Australian Dental Association and the Dental Hygienists Association of Australia, on how to address the very low risk of osteonecrosis of the jaw (ONJ) associated with anti-osteoporosis treatment).

## RECOMMENDATION 13

Develop a research program that includes a best practice audit for the diagnosis and treatment of osteoporosis and develop metrics to gauge outcomes for people with osteoporosis. Research topics would include:

- Identifying obstacles to, or opportunities for, closing the knowledge–practice gap in primary care, including why the current regime for screening for fracture risk is underutilised.
- Determining whether hospital-based FLS reduce the risk of subsequent fractures compared with standard management. Evidence from observational and smaller cohort studies indicate that FLS reduce the risk of subsequent fracture, however, this has not been proven in a rigorously designed and conducted randomised controlled trial (RCT). This level of evidence is necessary to justify the implementation of FLS across Australia.
- Research into the development and validation of new imaging methods to diagnose osteoporosis.
- Developing fracture-prevention strategies in Australian residential aged-care facilities.<sup>126</sup>
- Biochemical indices of skeletal turnover have the potential of aiding in risk assessment, as well as for monitoring of treatment. Their utility in clinical practice should be evaluated for use in diagnosis, prognosis and monitoring of treatment.<sup>127</sup>

## RECOMMENDATION 14

Develop a coordinated strategy to talk to state and federal government and the private health insurance industry about:

- Increasing support for streamlined and reimbursed diagnostic tests and treatments for women and men 50 years and over, and
- Broadening the range of triggering risk factors for diagnostic tests and preventative medication.

In Australia, there are conditions associated with reimbursement that sometimes interfere with diagnostic tests and treatments that physicians would normally recommend to their patients, including a lack of clarity around risk factors that indicate Medicare reimbursement for the need for a bone mineral density DXA scan.

In addition to a clear statement of recognition of osteoporosis as a National Health Priority, with incentives for health care providers in primary and secondary care to diagnose and treat osteoporosis, the streamlining of multiagency partnerships is necessary for accessible, cost-effective, integrated falls and osteoporosis care.<sup>131</sup>

In Australia, current Medicare reimbursement guidelines for a bone mineral density DXA scan includes:

- Pre-existing minimal trauma fracture(s)
- Women and men aged 70 years or over
- Female hypogonadism lasting more than 6 months before the age of 45 years
- Certain medicines – prolonged anti-inflammatory steroid (glucocorticoid) treatment
- Secondary causes – rheumatoid arthritis, hyperparathyroidism, chronic kidney or liver disease, male hypogonadism, proven malabsorption conditions (including coeliac disease), or conditions associated with excess glucocorticoid secretion or thyroxine excess.<sup>128</sup>

PBS reimbursement for primary osteoporosis prevention drugs is only for those aged above 70 years who have a T score  $\leq$  -2.5 on a DXA scan, or for those on long term anti-inflammatory steroid use with a T score of  $\leq$  1.5. Other conditions associated with reimbursement include prior fracture, subsequent fracture prevention, whether the drug is a first- or second-line treatment, and the requirement for an authorisation.<sup>129, 130</sup>



# 3. FINDING A CURE

Australia has been a world leader in osteoporosis and bone biology research for more than 40 years. From the Dubbo Osteoporosis project, the world's longest running epidemiological study in both men and women that continues to provide vital data to researchers locally and internationally, to research into osteoporosis resulting from metastatic breast and prostate cancer, Australia's researchers have a well-earned reputation for innovative and critically important translational bone research that impacts directly on individuals with skeletal diseases.

The exceptionally high quality research produced by Australian scientists also attracts the best international collaborators, placing Australia in an enviable position in terms of solving the critical puzzle of how to maintain bone health in an ageing population.

Australian osteoporosis research is in an unprecedented position to take advantage of the latest developments in genomics research and personalised medicine to more rapidly deliver new treatments that will prevent the onset of osteoporosis and improve the lives of Australians living with the disease.



## RECOMMENDATION 15

Develop a strategic plan for research into curing osteoporosis.

To cure osteoporosis, we need to be able to replace bone that has been lost in order to prevent fractures. To do this we need to really understand the causes of osteoporosis at a cellular, molecular and genomic level and to develop new drugs that replace bone as it is lost.

We need to develop agile multi- and interdisciplinary approaches to curing osteoporosis. This will include expertise in genomics, big data analysis, systems biology, computational science, chemistry, engineering, along with biology and medicine.

We need a unified approach to reduce duplication of efforts and identify opportunities for greater collaborations, nationally and internationally, and to create a critical mass of researchers working in large groups, linked to greater resources to deliver greater impact.

The Australian bone research community has a well-deserved international reputation.

Australian research highlights include:

- The discovery of parathyroid hormone-related protein (PTHrP) - a key regulator of calcium in the skeleton, from which an analogue has recently been developed to treat osteoporosis.
- The discovery that our genes significantly control the bone mass has led to studies worldwide to identify new genetic pathways that control our skeleton. The internationally linked Australian Osteoporosis Genetics Consortium has identified genetic variants that can increase the risk of having osteoporosis by up to 56% and increase the risk of all types of fractures by 60%.
- The unique Dubbo Osteoporosis Epidemiology Study, at 27 years the longest running study of osteoporosis in men and women to identify and predict risk and adverse outcomes (including premature mortality). From 1989 the population-based Geelong Osteoporosis Study has also been used to describe the burden of osteoporosis in the general population and to identify risk factors for fracture.
- Innovative studies that have shown how glucocorticoids (cortisone) negatively affect bone.
- New state-of-the-art imaging research that has given us a new understanding of the porosity of cortical bone and how this reduces its strength.
- Research that has shown that advanced breast and prostate cancers, which have travelled to the bone, and myeloma (a cancer which forms in the bone marrow) have dramatic effects on the skeleton, breaking it down or causing bone to form where it shouldn't. Studies have revealed that bone acts as a reservoir for dormant cancer cells which when awakened cause new active growing cancers that are very difficult to cure and cause devastating fractures.
- An increase in major international collaborations with Australian researchers working with and leading consortia addressing critical questions in osteoporosis research. These include the Genetics Factors of Osteoporosis consortium and the Wellcome Trust Origins of Bone and Cartilage Program.

## RECOMMENDATION 16

Develop new bone anabolic drugs that actually build new bone to treat osteoporosis.

We currently have drugs that stop further bone loss, but they don't increase the amount of bone. We need to develop drugs to replace lost bone and improve bone quality to prevent fragility fractures. This will require:

- Understanding the critical cellular and molecular pathways that control bone strength
- Development of new drugs that target regulators of bone strength to make new bone and improve bone quality

## RECOMMENDATION 17

Develop the tools to evaluate new bone building drugs, including response to treatment.

We need the tools from bone biomarkers in the broadest sense, through to new kinds of imaging to understand if and how new treatments are effective.

We also need tools to identify those who will benefit from specific interventions, such as genomic or pharmacogenomics approaches, as well as better ways to evaluate new drugs in preclinical trials.



Prostate cancer metastasis to bone. Courtesy Bone Biology Division, Garvan Medical Research Institute..



### CHRISTINE RYAN

When Christine Ryan was diagnosed with breast cancer in 2015, she focused on getting well, with chemotherapy, radiotherapy, Herceptin infusions every three weeks and a five-year course of Letrozol.

'Prior to treatment for breast cancer, my only other health issues were a hiatus hernia and a fracture from a foot injury in 2011,' said Christine.

As part of her breast cancer treatment, in early 2016 Christine's oncologist referred her to an endocrinologist and x-rays of her thoracic and lumbar spine showed osteopaenia.

Christine was 61 at the time, living on her own and running her retail consulting business. Christine also works with her dog as part of volunteer therapy at the Sydney Children's Hospital, Randwick and Prince of Wales Hospitals.

'Although my oncologist prescribed calcium and vitamin D supplements, I'm still concerned about the impact of Letrozol on my bone density down the track.'

The endocrinologist prescribed six-monthly Prolia (denosumab) injections from March to protect her bones, but Christine is not entitled to a Medicare subsidy and pays \$400 for each injection.

Christine's sister was recently also diagnosed with breast cancer and will shortly begin Letrozol. Her mother developed a significant curve to her spine in the later stages of her life.

While Christine is feeling well and confident that her breast cancer is behind her, she is concerned to protect her bones from the impact of her cancer drugs.

'Other than cursory discussions on the benefits of exercise to counter loss of bone density, there has been no support in this regard. At the Epworth Hospital in Victoria there is a post breast cancer treatment rehabilitation program which includes nutrition and exercise physiology to target the impact of cancer drugs on bone density.

'In Sydney, however, I haven't been able to find an exercise physiologist to help me. Given the negative impact that Letrozol will have on my bones, I find the lack of this kind of treatment in NSW very worrying.

'I would dearly love some guidance in terms of nutrition and an exercise plan specifically addressing the impact of Letrozol on my bone density over the next five years. As it is, I rely on Professor Google to develop my own plan.'



## PROFESSOR BRUCE ARMSTRONG AO

In 2005, aged 61, Professor Bruce Armstrong had a chest x-ray for suspected pneumonia that showed 'mild osteoporosis' with some damage to the spine.

'Until that point, apart from some episodes of pneumonia and a slightly irregular heartbeat, my health had been excellent,' said Bruce. 'I was not aware of any trauma that might have caused the damage to the spine or of any back pain.'

No treatment was suggested at the time, and although Bruce was advised in 2007 that he 'should do something about the osteoporosis', it still wasn't a priority. Only when a bone mineral density (BMD) test in 2015 showed worsening osteoporosis did Bruce agree to go on an 18-month course of teriparatide (to replace lost bone), with a combination of much increased dietary calcium, some use of calcium tablets and a regular program of weight-bearing exercise.

'My mother had increasing back deformity during the last 10-20 years of her life, which could only have been due to osteoporosis, and my older sister also has osteoporosis and has been taking calcium and bisphosphonates (to prevent bone loss) for a number of years.

'I am now fit and healthy, physically active and largely free of any back discomfort. Apart from the spinal damage, I have had no fractures.

'I qualified in medicine and work in medical research, but somehow, I never really took seriously the potential impact of osteoporosis on my health until the specialist told me in October 2015, then age 71, that I had the spine of a 90-year-old!

'I suspect that I have had a low to very low calcium intake for all of my adult life until now and I always believed that aerobic exercise was sufficient to keep me healthy. If this was my level of ignorance, even though I've had medical training, what can we expect in the general community?

'While there are many things that might be done to improve the situation, raising awareness of the risk and how to reduce it, is the highest priority. I also strongly support initiatives that ensure that people who have had a fragility fracture, don't have subsequent ones.'

## RECOMMENDATION 18

Develop partnerships between researchers in oncology, endocrinology, immunology and other fields into comorbidities and secondary causes of osteoporosis, including cancer-induced bone loss.

People with osteoporosis often have multimorbidities, including muscle weakness, cardiovascular diseases, hypertension, diabetes mellitus, metabolic syndrome and osteoarthritis, to name a few. On average, a person with osteoporosis has three co-diseases, the presence of which contribute to worsen the patient's bone health. Many of these diseases are related through environmental exposure and common genetic factors. Interdisciplinary research is needed to construct a network map of co-morbidities associated with osteoporosis and to determine shared risk factors, environments and genetics, for co-occurrence of diseases.

## RECOMMENDATION 19

Develop a translational strategy to see new drugs are quickly made available to the community.

As a matter of urgency we need partnerships with the pharmaceutical industry to test new and pre-existing drugs that may be repurposed to improve bone health.

We need new trial designs to rapidly transition new and repurposed drugs into clinical research programs to benefit patients.

We also need partnerships with professional bodies and consumer organisations to mobilise the wider community to take up these new drugs to protect Australians from osteoporosis.

## RECOMMENDATION 20

Develop a funding stream to ensure the necessary long-term research that will cure osteoporosis.

We need to develop a national strategy to raise government and community funds to specifically fund osteoporosis research in Australia. This would include activities ranging from leveraging the new Medical Research Future Fund, through raising levels of philanthropy to support osteoporosis research, to utilising novel methods of raising research funds such as crowdsourcing using social media.





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Front cover image shows osteoporotic bone.  
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