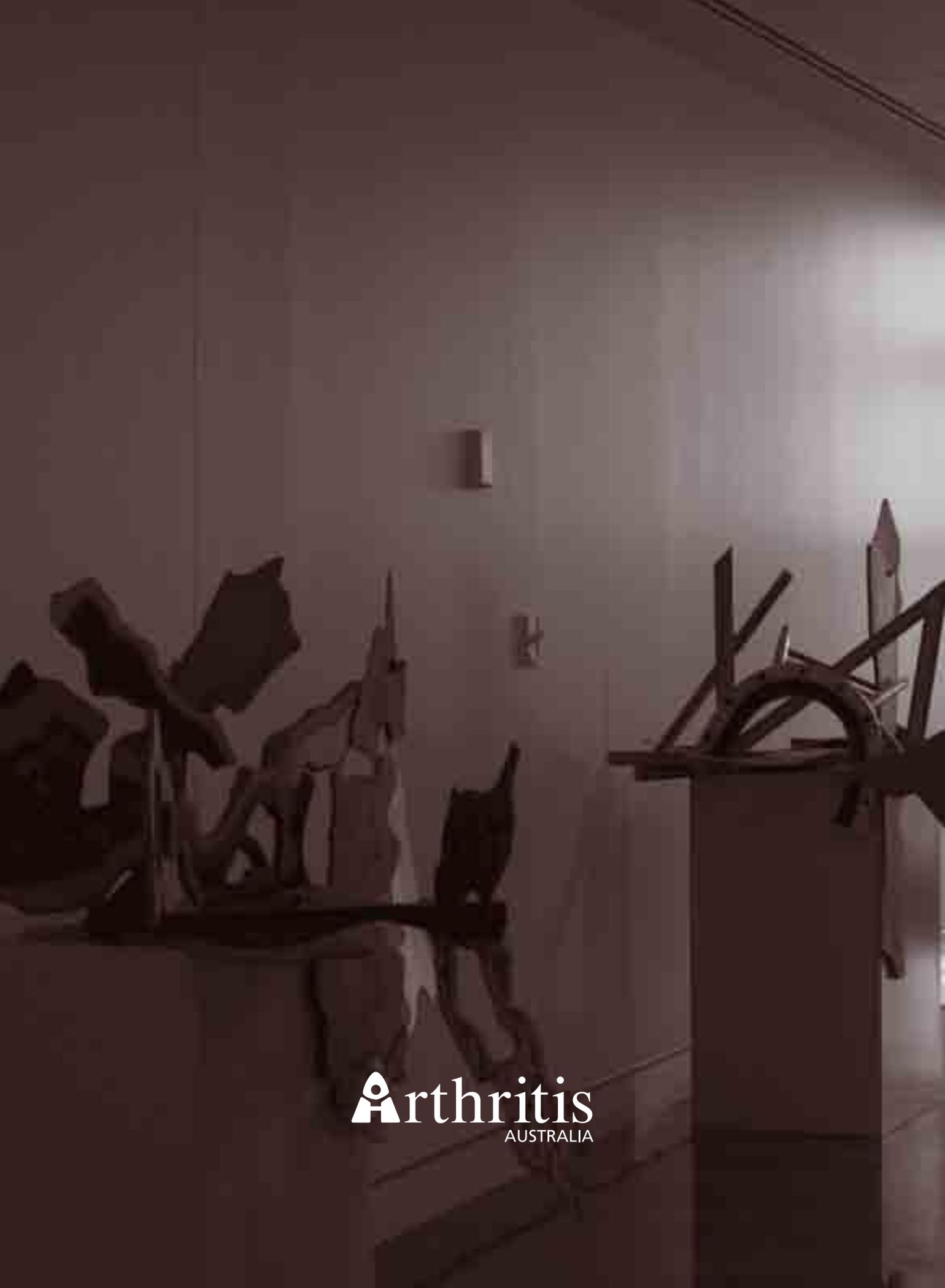




Women's Insights into Rheumatoid Arthritis





 **Arthritis**
AUSTRALIA



Women's Insights into Rheumatoid Arthritis

Arthritis Australia is the peak arthritis organisation in Australia. It is a not-for-profit organisation and is supported by affiliate offices in every state and territory.

Our Vision is...

To bring quality of life to all people with arthritis and reduce their suffering.

Our Mission is...

To provide dignity, support and education for Australians suffering from arthritis and their carers.
To radically restrict the rate of growth of arthritis in Australia.
To be a leader in funding and advocating world class research.

Arthritis Australia...

Provides support and information to people with arthritis as well as their families and friends.
Promotes awareness of the challenges facing people with arthritis across the community, and to leaders in business, industry, and government.
Funds research into potential causes and possible cures as well as better ways to live with arthritis.
Aims to keep health professionals such as physiotherapists, occupational therapists, and community nurses informed.

“Many tears have been shed in the telling of stories for this book.”



I am pleased to have been asked to write the foreword to this special project. *Women's Insights into Rheumatoid Arthritis* is an important initiative of Arthritis Australia and brings women living with rheumatoid arthritis – or RA as it's often called – in personal contact with our nation's federal politicians, all of whom have a role in shaping Australia's health policy.

We know that many of the politicians have had their eyes opened about RA and now have a better understanding about this chronic disease. Arthritis Australia deliberately chose female politicians as we felt the women who had volunteered to share their stories with them, and everyone who reads this book, would feel more comfortable in their company.

It has been difficult for our RA champions – for that's what they are – to think back over the progression of their disease from when they were first diagnosed, through the years of endless pain and the many ways in which RA has changed their lives. Not surprisingly, tears have been shed in the telling of their stories. I defy anyone not to be moved by their courage and their incredible optimism. It's heart-warming stuff.

My involvement in the arthritis cause dates back to the early 1980s when my daughter Kate, was diagnosed with “a rare form of juvenile arthritis”. She was then 14. There was quite a long period – or so it seemed at the time – when doctors were unsure what was wrong with her. She had to undergo many tests. We made a visit to the Sydney Children's Hospital where Kate and I were questioned by a roundtable of doctors for a couple of hours. We left none the wiser as to what was wrong with her.

One night she even asked me if she was going to die and in a way, it was almost a relief when her arthritis condition was diagnosed. I know she felt

“different” to the other girls at her school, something no teenager ever wants to be. She was in considerable pain and unable to continue playing tennis and the piano. She never complained though but just got on with doing what she could manage and her studies didn't suffer.

Fortunately, Kate's story has a happy ending. Her treatment was successful and one day her rheumatologist announced that in his opinion, she was 98 per cent cured. By the time, she completed her university studies she was captain of Sydney University's ladies tennis team. She is now the mother of two daughters and in good health.

I remember Kate's doctor telling us that arthritis is a silent disease because people who have it look “normal”. The women featured in this book say that time and time again. So please remember that you can't tell by looking if someone has RA. Nor is it a disease of only older people. It also affects more women than men.

Over the years, I've served as national spokesperson of Arthritis Australia and also as its President. In 2009 I was honoured to be appointed Vice President Emeritus. One of my most recent tasks has been to edit this book. I enlisted the help of Kate for proof-reading. When she returned some of the proofs to me she added this message. “I was lucky wasn't I? Hopefully, my arthritis will never flare up again. They all describe the pain accurately.”

As I read it my heart lurched a little. I had no idea Kate's pain had been that bad. Editing *Women's Insights into Rheumatoid Arthritis* has been a learning experience for me. I hope reading it is for you too.

ITA BUTTROSE AO, OBE
Vice President Emeritus
Arthritis Australia

“The most powerful tool we have to beat the crippling effects of RA is knowledge.”



Every day at my rheumatology practice in the western suburbs of Sydney I see the profound effect rheumatoid arthritis has on people’s lives. I have watched my patients struggle with the pain of a chronic disease, cope with education and work, relationships, child-bearing and old age.

Mostly they have managed with good humour and courage. It’s a privilege helping them in their life’s journey but I am constantly frustrated by the general perception that RA is trivial.

When I first entered rheumatology, treatments were limited, sometimes toxic and often ineffective. Not surprisingly, doctors gave drug therapy sparingly and late. Over the years, many people suffered pain, progressive joint deformity and disability.

Now we know irreversible joint damage occurs in the first two years of RA and that earlier and more aggressive therapy can prevent or slow down its devastating effects. But still many people don’t understand the urgency of this situation, believing arthritis is all one disease, shrugging it off as an old people’s problem, and thinking nothing can be done.

Women’s Insights sets out to change these

misconceptions. RA is a serious condition. It can shorten life. It attacks people in their prime – often in their 30s and 40s – and affects women twice as often as men. Early action is vital.

The fight against rheumatoid arthritis has been enhanced by research which has allowed the development of new and life-changing treatments. However, biological therapies come with a hefty price tag, and the ongoing challenge is to work out how they can be funded, who should get them and when.

Overall, the most powerful tool we have to beat the crippling effects of RA is knowledge. The more people Arthritis Australia can educate about RA, the better the chance of ensuring that those living with RA are adequately supported and feel less isolated.

We are proud to share the stories of these special women with RA in the hope that their insights will inspire many more Australians to join our effort to minimise the impact of this disease now, and to encourage the research which will, in the future, find a cure.

DR MONA MARABANI
President, Arthritis Australia

In an average high school of 800 students with 1600 parents and 6400 grandparents, there would be at least 80 students – one in 10 – with a parent or grandparent with RA. Their lives would be directly impacted by the disease. This doesn’t allow for relatives and friends. Thus, almost everyone knows at least one person living with RA.

“Arthritis Australia’s aim is to broaden understanding about RA.”



As Chief Executive Officer of Arthritis Australia I have the privilege of leading the voice of arthritis in Australia – raising community, business and government awareness about its many forms and trying to get a better deal for those struggling to overcome its debilitating effects.

It isn't an easy job. Few people understand what people with arthritis go through and too many fail to realise the huge personal cost it wreaks. As someone living with RA once told me, “You don't die from arthritis but it can be a living hell.”

I can't help admiring the many brave and determined people I meet who are grappling to manage their RA. Through our range of practical information and support services, my colleagues and I get a kick out of helping Australians gain confidence and learn to manage their disease.

Women's Insights is an attempt to raise the voice of RA and make it heard. Through the untold stories of 12 wonderful and gutsy women we're hoping to broaden general understanding of the disease in the belief that better knowledge will help reduce the

effects of RA in Australia and ultimately limit the impact on future generations.

Too many Australians with rheumatoid arthritis are not being diagnosed and treated quickly enough. We want to ensure:

- Australians understand the warning symptoms and the importance of consulting their GP immediately
- GPs are up-to-date with the latest RA information and will refer their patients to a rheumatologist for a proper diagnosis and management plan
- Australians take control of their RA and actively pursue quality health care and proper support from their family
- Decision makers understand the seriousness of RA and support those in need.

Most of all I want to assure anyone living with RA that you are not alone. There are many people including all of us at Arthritis Australia, who want to help you attain the fulfilling life you deserve.

AINSLIE CAHILL

CEO – Arthritis Australia

The greatest share of arthritis costs in Australia is borne by individuals with arthritis themselves who, principally due to the large burden of disease costs, bear 61 per cent of total costs. Twenty-one per cent of total costs are borne by the federal government due to the high health and productivity costs, while a further nine per cent are borne by society.



The facts about rheumatoid arthritis

What is rheumatoid arthritis?

Rheumatoid arthritis (RA) is the most serious form of arthritis. It is an autoimmune disease that causes pain and swelling of the joints. The normal role of the body's immune system is to fight off infections.

When a person has an autoimmune disease, the immune system starts attacking the body's healthy tissues. In the case of rheumatoid arthritis, the immune system targets the lining of the joints, causing inflammation and joint damage. RA usually affects smaller joints, such as the joints in the hands and feet. However larger joints such as the hips and knees can also be affected.

What are the symptoms?

The symptoms of RA vary from person to person. The most common symptoms are:

- joint pain, swelling, and tenderness to touch
- stiffness in the joints, especially in the morning
- the same joints on both sides of the body are affected
- fatigue and depression

Who gets it?

RA affects 2.5 per cent of Australia's population. This means that around 520,000 people live with the disease. It is more common in females who also tend to develop the RA at an earlier age than males. The disease onset occurs most often between the ages of 35-64 years. An estimated 57 per cent of people with RA are women.

What causes it?

It is not known what causes RA. It is more common in people who smoke and/or those who have a family history of RA.

How is it diagnosed?

A doctor will diagnose RA based on symptoms, a physical examination and various tests.

These can include:

- blood tests for inflammation
- blood tests for rheumatoid factor
- x-rays to see if joints are being damaged by the disease.

RA affects people of different ages, race and sex and is twice as common in women than men. RA can be managed but not cured.

It can be difficult, and often takes quite some time, to diagnose RA as the symptoms can be similar to other types of arthritis. If a doctor suspects a patient of having RA, the patient should be referred to a rheumatologist, a doctor who specialises in arthritis.

What happens to people with RA?

With early diagnosis and the right treatment, most people with RA can lead full and active lives. However the course of RA varies and no two cases are the same. Many people with RA experience “flares”, periods when joints become more inflamed and painful. These can happen with no obvious cause. Flares are commonly followed by months or even years of little inflammation. RA can cause permanent joint damage and deformity, especially in the first few years of the disease. The good news is that early diagnosis and treatment is shown to limit this type of joint damage.

Is there a cure for RA?

Currently there is no cure for RA. However treatment has improved dramatically over the past 20 years, with new medicines now extremely helpful for people in the early stages of RA.

What treatments are there for RA?

A rheumatologist will tailor treatment to a patient’s symptoms and the severity of their condition. There is no way of predicting exactly which treatment will work best. A rheumatologist may need to trial several different treatments before finding the one that is right and this treatment may include medicines, such as:

- non-steroidal anti-inflammatory drugs (NSAIDs)
- corticosteroid medicines or injections
- disease-modifying anti-rheumatic drugs (DMARDs)
- biological DMARDs, such as tumour necrosis factor (TNF) medicines
- exercise, to keep the joints flexible and muscles strong.

Further information is available on the Arthritis Australia website at www.arthritisaustralia.com.au

The rheumatoid factor

The rheumatoid factor (RF) is an antibody (a protein made by the body’s immune system). It is found in about eight out of 10 people who have rheumatoid arthritis, but two out of 10 people with RA will never test positive for rheumatoid factor.

Rheumatoid factor levels can also vary and the test results may be negative in the early stages or during inactive periods (remission) of RA.

If you have symptoms of RA but your rheumatoid factor test is negative, your doctor may order the test to be repeated. However a positive rheumatoid factor test does not always mean you have RA as there are several other conditions that can also give positive rheumatoid factor results.

Healthy people with RA can also test positive for rheumatoid factor, particularly older people. This does not mean they will develop the condition.

Exercise and RA

Exercise is an important part of managing RA. People with RA who exercise have:

- Higher levels of fitness
- Better muscle strength and size
- Greater ability to do daily tasks
- Improved mood and emotional wellbeing.

Exercise can also help you maintain a healthy body weight and improve the health of your heart and blood vessels. Some types of exercise may also help improve the strength of your bones and reduce your risk of osteoporosis.

Many people with RA are anxious about exercising. This may be due to fear of causing damage to the joints or the presence of pain. However research shows that people with RA can participate in regular, appropriate exercise without causing joint damage or worsening of symptoms.

Before beginning any exercise program a person with RA should talk with their rheumatologist to find out if there are activities they should avoid. It may also be useful to ask a physiotherapist for advice on exercising safely.

“I’d promised to make a salad but my hands and wrists were so painful I couldn’t slice the lettuce. I felt so helpless. All I could do was stand there and sob.”

Elleke Penny

Since her diagnosis at 35 Elleke has not had one day without pain yet she has managed to raise two children and hold down her job as a kindergarten assistant for 30 years. Working helps her to cope with a disease over which she virtually has no control, she says.

Elleke Penny was two-and-a-half when she immigrated to Australia from the Netherlands with her parents and two brothers. It was 1952 and although World War Two had ended seven years before, her father still suffered from his time in a brutal German work camp.

Four more children were born after the family settled in Victoria but her father’s difficulties compounded, particularly after he was diagnosed with RA.

“At the time, everyone thought it was the result of the deprivation he’d suffered in the work camp where he was forced to sleep on concrete. When he

was released his weight had dropped to just 38 kilos,” says Elleke, who lives in Sunbury, Victoria.

No one in the family realised RA could be passed on but when Elleke began suffering pain in her hands and feet, she knew instantly what it was. Insisting her GP refer her to a rheumatologist, she was given a series of tests which confirmed her worst fears. She had RA. She was 35 and had two children – Simon who was 11 and Natasha aged eight.

Her first reaction Elleke says was anger. But remembering her father and how difficult and bitter he had become, she was determined not to go down that route. She chose instead to look to her mother





Elleke Penny met with Julia Gillard.

and the other strong women who had helped raise her, for inspiration.

"My mother has always been my role model. She arrived in Australia knowing no one, with no friends and no family of her own, and made a life for all of us while coping with Dad, which wouldn't have been easy." (Elleke's father left his family to return to Holland in 1970.)

Elleke also drew strength from three female neighbours from her childhood. "A World War One widow lived next door with her daughter and also her step-sister. They 'adopted' me as their own when I

special knife and fork to help her eat. "I hated using that knife and fork," she says, but concedes they did help her to function. There were days though when her hands were so stiff and swollen she had no grip and the aids were as good as useless.

"One morning we were off somewhere with friends. I'd promised to make a salad but my hands and wrists were so painful I couldn't slice the lettuce! I felt so helpless that all I could do was stand there and sob."

Despite her pain and difficulties, Elleke has continued to work as a kindergarten assistant and has held her job for the past 30 years. She loves

Elleke credits her rheumatologist for helping foster her positive attitude about living with RA.

was about three and through their example I learned how strong women can be and how we can cope with pretty well anything life throws at us."

Treatment for Elleke's RA started as soon as she was diagnosed but in 1989 she became so ill she had to be hospitalised. She then spent several weeks in rehabilitation. "When I came out I felt like an 89-year-old. I walked like one too! I had no energy at all and could barely move my feet."

To prevent her hands bending backwards or her fingers curling and her joints deteriorating further, Elleke had to wear specially-made hand splints during the day and rest splints at night. "The night splints went from my elbow past my wrists to my hands. Wearing one on each arm made it impossible to sleep. Then someone told me I should be alternating them, wearing one on one night and the other the next! When I tried that, sleep became a whole lot easier," she says laughing.

A self-confessed perfectionist, Elleke admits that one of the hardest things was learning to relinquish control. "My husband would help by hanging out the washing or cooking meals. But he'd peg out the clothes any old how, insisting they would dry just as well and I found that really frustrating. It was the same when he cooked meals. He didn't do things the way I did and that upset me. In the end, I had to let go."

In addition to wearing splints in bed at night, Elleke was given a variety of aids to help her turn taps on and off, open cans and turn keys, as well as a

it. "Before I married and had kids I was a laboratory technician but after Simon and Natasha came along, I wanted a job where I could be home to greet them when they came home from school and be with them during school holidays."

Being able to work gave Elleke a feeling of independence and control while coping with a disease over which she had virtually no control.

In the mid-1990s, her marriage broke up and suddenly forced to be the family's main breadwinner, she had to battle to keep the family home as well as hold down a job. Stress can be a big factor in triggering an RA flare and not surprisingly in 1999, Elleke's condition worsened. Hospitalised once again, it was found that along with RA, she also suffered from osteoporosis caused in part by her disease and also by the strong doses of medication used to control it. She was also diagnosed with stenosis, an inherited condition that causes spinal degeneration. The pain in Elleke's back was so intolerable that she needed an epidural.

Although many RA patients go into remission for months or even a year or two at a time, since her diagnosis, Elleke has not had a full remission. But she says the fantastic improvements in medication over the past few years have made her life much easier and allowed her to continue working and remain independent.

She is enormously proud of her children – Simon is with the Australian Federal Police in Canberra and

multi-lingual Natasha works for a company in Japan. This means though that she has no family living nearby so long-term friends who also live in Sunbury have become her "surrogate" family. They have keys to her house so they can check on her and pop in to help her get ready and zip up her dress if she is going out to dinner. "If no one's around, I'll ask my hostess to zip me up when I arrive and then unzip me before I get in my car to go home," she says.

To increase her fitness and build up her muscles to protect her joints, Elleke does weight training at a gym three times a week. After breaking her humerus (the bone of her upper arm) in 2000, she also spent part of every Sunday at the local pool for some months doing her own version of "hydrotherapy" to help get movement back into her arm.

She is an inveterate traveller and in September 2009 travelled to Japan to see Natasha, then toured China and walked the Great Wall. Before embarking on the trip, she was denied travel insurance but typically, she refused to take this lying down and put up a strong fight, arguing that if her GP and rheumatologist believed she was well enough to travel, there should be no impediment to giving her insurance. She won the day! Elleke refuses to be limited by her RA and intends to do as much travel as possible "while I can".

The person she credits with helping foster such a positive attitude is her rheumatologist. "He diagnosed me 24 years ago and is not only my doctor but my friend. He asks 'How are you? Not how are your joints?' He sees the entire person, not just their disease and that's really important."

The Hon Julia Gillard MP

Deputy Prime Minister*

Member for Lalor, Victoria

"Until I met Elleke I didn't realise that RA was so disproportionately a disease of women."



I've long known that RA is not a disease limited to old people. However I was unaware that splints were used to help prevent deformities of the joints by physically manipulating hands and arms to ensure they stay in as normal a position as possible.

A friend of mine with RA had a baby 12 months ago and had to endure the experience of going off all medication during her pregnancy. She then had a severe flare up of the disease after the birth. But I didn't realise that the onset of RA could be as dramatic, or occur as rapidly, as it did with Elleke

Living with something as unpredictable as RA must be a huge burden. You wouldn't be able to plan a

holiday for instance without worrying that your health might suddenly deteriorate forcing you to cancel the trip. The prospect would always cancel out those joyful moments of anticipation.

I can see that it's important to have a great doctor who can navigate the specialist care someone with RA needs but what's also needed is community education about the disease to bring about widespread understanding that it is not only older people who suffer from RA.

***Ms Gillard is also Minister for Employment and Workplace Relations, Minister for Education and Minister for Social Inclusion.**

“Elleke is very gutsy and is a continual inspiration to me.”



When Dr Richard Travers first qualified as a rheumatologist, he thought his job was to cure arthritis. “It was tough to realise that I couldn’t do this. I now ask myself how I can be helpful and mitigate the pain and stiffness,” he says.

His focus these days is on doing whatever he can to help control the disease. “Living with unremitting pain can be very tough for those who have RA. Sometimes it goes into remission which is lovely but often it doesn’t.”

Most people with RA do, at some point, experience a form of remission that may last a month or two, or even many years. However, Dr Travers says, for Elleke there has never been a remission or a day absolutely free of pain since she was first diagnosed.

Elleke often needs joint aspiration and injections with cortisone to ease the inflammation. For some patients, cortisone injections are the only treatment that brings relief. Dr Travers says he mentions this because he is concerned that cortisone injections are no longer subsidised by the government.

“In most cases the extra pain is the result of a flare of RA, but occasionally it is the result of joint

infection. Examining the joint fluid is the only way to be sure. However, the Federal Government recently removed the rebate for this procedure. This means, until the Government addresses this issue many in need, including Elleke, are left with an added expense they can’t really afford.

“RA is already an expensive disease and I worry that some people will forgo an injection and put up with severe pain because they cannot afford to pay for cortisone injections.”

Dr Travers says Elleke is a continual inspiration to him. “She is currently doing well,” he says. “Sometimes there is more swelling and pain in her joints than at other times but right now her joint count and acute phase reactants do not qualify her for subsidised therapy with biological agents.

“Elleke is very gutsy and despite having severe RA has always managed well and is someone who refuses to be defeated by her disease, and that’s a wonderful thing.”

DR RICHARD TRAVERS
Rheumatologist – Victoria

There are more than half a million
Australians living with the disease.
An estimated 57 per cent of them are women.



“I rang eight different organisations for some home help after I’d had Oscar. They all told me I didn’t fit the criteria. There’s no funding to help someone young with RA like me.”

Suzie May

Diagnosed with RA at 27, Suzie May was still determined to become a mother and despite months of unrelenting pain, has no regrets.

“Not having children was never an option,” she says. “The first thing I asked my current rheumatologist was whether I could have children.”

The rheumatologist analysing the battery of tests Suzie May had undergone pulled no punches. “You have rheumatoid arthritis,” he said flatly. “There’s no cure and you will have to take chemotherapy drugs for the rest of your life.”

For 27-year-old Suzie, that was shock enough. But the doctor hadn’t finished. “The drugs may also cause liver damage,” he warned. “You don’t want to have children do you?”

In shock, the young law graduate fled the rheumatologist’s office and took refuge in her car. “I sat there screaming the loudest I have ever screamed in my life,” she says. “And then I rang Chris,

my partner – now my husband – and tried to make some sense of what I had been told.”

Suzie never went back to that rheumatologist. Instead she searched for one who was on her wavelength, that she could trust and who would encourage her to become actively involved in her own treatment.

“I discuss and make every decision with the rheumatologist I now have whether it’s about a change in medication, a new type of treatment or the latest research.

“We are a team and he never treats my questions as silly or wrong or of not deserving an answer.”

Suzie May met with Julie Bishop.



At the time of her diagnosis Suzie was fit and full of energy. She had studied ballet from age three until she was 17, she walked at least four times a week and had just taken up jogging. She and Chris had recently enrolled in South American dance classes where they were having the time of their lives learning to tango.

Suzie's career was also in great shape. In 2002, after several years working in social welfare, she had graduated from The University of Western Australia with a law degree and had been offered a chance

children was never an option," she insists. "They were always part of my life plan and when I found my current rheumatologist, the first thing I asked was whether or not I could have children."

"There's nothing to suggest you can't," he said. But to ensure the safety of her unborn child, he told her she would have to stop all medication before becoming pregnant as well as during her pregnancy and, if she intended to breastfeed, for up to six or seven months.

This he warned would not only mean intense pain

"I can't believe after all the pain during the pregnancy how perfect Olive is."

to do her articles at one of Perth's best-known law firms. But in March 2003, one week before she was due to start, she was diagnosed with RA.

Her symptoms had begun the previous July when the sides of her feet and her little toes were so painful she had difficulty walking. The pain was initially put down to stress fractures caused by pointy-toed high heels. But a change in footwear made no difference and by late November 2002, the pain was so severe that Suzie was unable to walk at all. Diagnosed three months later, she was given cortisone injections and other prescribed medications but the disease spread rapidly. Within three months her entire body was affected.

"I kept the diagnosis secret not wanting it to impact on my new job but by September 2003 I was so ill I needed a big chunk of time off."

Suzie's bosses were sympathetic but like many of her friends and colleagues, were unable to understand how she could seem so well one day and be so ill the next. They couldn't grasp that RA can change not only day to day but hour to hour.

Typically Suzie refused to give in and by the end of 2003 was admitted to the Supreme Court of Western Australia as a solicitor. She loved her work as a lawyer but in 2005 decided to set up her own consultancy at home. "My RA had become so unpredictable that it was easier to work from home where I could be more flexible with my hours."

Suzie and Chris married in March 2005 and almost immediately began trying for a baby. "Not having

but without the latest in modern medicine to protect them, her joints would also deteriorate.

But as Suzie says with a smile: "I've always been determined and when I was diagnosed I decided I could lie down and let the disease take over my life, and ignore my dreams and my future. Or I could stand up and fight and still achieve all the things in life I wanted."

Admitting that this positive outlook doesn't mean there aren't moments when she falls down in a heap and has to fight self pity, Suzie refuses to let RA define or overwhelm her. And with a baby as her most cherished dream, she enrolled in a self-management course with Arthritis Western Australia to learn alternative ways to manage pain using heat packs, rest, diet, hydrotherapy, meditation and positive visualisation. Then she discontinued her medication.

Managing pain didn't mean it was eradicated and after weeks of agonising flare ups, Suzie had to accept the fact that she would have to put her business on hold to achieve her long-held dream of becoming a mum. Three months later she learned she was pregnant and in June 2007 Oscar, a healthy baby boy, arrived. "He was delivered by Caesarean and was everything I could have hoped for," she says proudly.

Seven days after Oscar's birth, Suzie suffered post birth flare. The next 10 weeks were sheer agony. She couldn't even turn over in bed by herself. Each morning Chris had to prop her up on pillows, give her small doses of an anti-inflammatory steroid, then lower Oscar on to her breast. A firm believer in breast milk, Suzie learned to scoop up her son using her

forearms rather than her painfully swollen hands and no matter how much it hurt, insisted on cuddling him at every opportunity.

Suzie has written a book about her pregnancy and her first year as a mother. It is filled with advice from her own experience as well as first person stories from mothers and fathers worldwide who have had children while living with RA and other chronic conditions. Due out in March 2010, the book details the joys as well as the difficulties of having a baby. "I hope it helps people with RA to make an informed decision and to not feel so alone," she says.

Now 35, Suzie gave birth to her second child, Olive Amelia May, on February 19, 2010.

"She's beautiful and turns her head towards Oscar when he talks. I can't believe after all the pain during the pregnancy how perfect she is. I know I'll have to go through the post birth flare up again and wish there

was some sort of home help support I could turn to," she says wistfully. "Someone to come in for an hour or two in the morning to make the beds, throw things in the washing machine and help prepare meals."

After Oscar was born Suzie rang eight different organisations for help with the running of her home but was told she was too young and didn't fit their criteria. "Meals on Wheels help older people but there's nothing for people in their 20s and 30s with RA. There's no funding to help us with shopping or the running of a house or things that can be problematic during flare ups. Everyone just assumes that because we're young we can cope."

Despite such difficulties Suzie has not had a moment's doubt about her decision to become a mother. "People sometimes ask is having a baby worth it. For an answer all Chris and I have to do is look at Oscar and Olive. They are both so precious."

The Hon Julie Bishop MP

Deputy Leader of the Opposition*
Member for Curtin, Western Australia

"I cannot imagine what went through Suzie's mind when her RA was first diagnosed."

Her story really brought home to me the gap in service delivery. Having an age criteria for services doesn't recognise people of a younger age with RA, like Suzie, who need support. There is clearly a need for policy intervention.

Having trained and practised as a lawyer myself I can understand a little how Suzie, a young woman with a promising legal career ahead of her, must have felt to have been told she had RA.

But her positive attitude and the unconditional support of her husband, has seen her continue on and

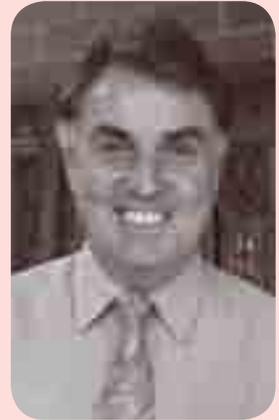


set up her own legal consultancy. Suzie is a poignant, beautiful young woman with a degenerative disease who is determined to carry on with her life. I found her so brave, sincere and selfless.

Her story is a reminder of how RA can affect anyone of any age. It is also a reminder that for this disease, there is no cure."

***Ms Bishop is also Shadow Minister for Foreign Affairs. She is a member of Arthritis Australia's Parliamentary Friends of Arthritis.**

“I love the fact that my practice now has babies everywhere. It’s great.”



“New medications and treatments for rheumatoid arthritis have changed the landscape for women with RA,” says Dr Ken Maguire.

“Not only do they now have a high chance of functioning as ‘normal mums’ but pregnancy is also more comfortable for them and has come a long way since the days of gold injections and bed rest.”

Women, who once thought they would be never able to have children or had chosen to remain childless because of their illness, now have the option to become mothers. And Dr Maguire who admits he is “clucky about kids” couldn’t be more delighted. “We’ve had dozens of pregnancies in the last few years. They really brighten up the place for everyone.”

But becoming pregnant also means coming off most of their medications to prevent any damage to the baby in the womb.

“With Suzie we were able to manage her pain with joint injections of cortisone from time to time. She also took a very low dose oral cortisone.”

The hormonal effect of pregnancy seems to protect the body and Dr Maguire says the disease is often far less active during this time.

“Symptoms of RA may become mild but after delivery flares can occur.”

For women like Suzie who want to breastfeed, postnatal flares cannot be treated by any of the powerful medications used to control the disease. Therefore it may be suggested that breastfeeding should be minimal on the grounds that the child benefits more from a well mother than one who is in constant pain.

RA mothers whose babies are formula fed can immediately resume their prenatal medications.

Most women with RA have no difficulty conceiving. These days, although not common practice, some women of childbearing age who have been diagnosed with RA put embryos in storage at fertility clinics so they can become mothers at a later time (in much the same way as young women with cancer have their eggs harvested prior to chemotherapy). Men with RA sometimes arrange to have their sperm stored for when they want to start a family.

DR KEN MAGUIRE

Consultant Rheumatologist

Perth Orthopaedic and Sports Medicine Centre

RA is more common in people who smoke and/or have a family history of the disease.



“My joints weren’t disfigured and I didn’t look sick. Because there were no physical signs that anything was wrong I know some people dismissed me as a hypochondriac.”

Ann Goody

RA is rare among Australia’s indigenous population but Ann Goody was diagnosed with it when she was 41. One of her brothers also had RA when he was a child. RA changes everything she says. It has taught her patience and to accept that she needs to rely on others for help.

They breed them tough in Central Queensland and Ann Goody is no exception. At 38, she could literally turn her hand to anything whether it was mustering a herd of half-wild Herefords, wielding heavy machinery or digging a new dam.

This mother of four was also a crack shot, a keen gardener and made beautiful leadlight designs as a hobby. Then about 18 years ago, when their two sons were teenagers and their two daughters were in their early 20s, Ann and her husband felt like a change. They decided to sell their cattle property near Injune, a small town nestled in the Great Dividing Range, and move to Cooktown in the far north of Queensland.

“That’s when we bought the bulldozers,” she says. “We had two of them. He would drive one and I’d drive the other. They enabled us to make a bit of extra money clearing trees, putting in roads and digging dams while we made the move.”

The relocation took almost two years. Every few weeks, Ann would pack up the farm’s big truck with some of the family’s possessions and head for Cooktown. The drive took almost two full days and nights with stops only for food or petrol. Once there, she’d unload the truck and camp out on one of the two rural lots she and her husband had bought. Then after a brief rest, she would make the long drive back

Ann Goody met with Senator Sue Boyce.



to Injune, where once again she would take over the controls of one of the bulldozers and fulfil whatever contract work had come in while she had been away.

It was a daunting schedule but Ann thrived on the challenge. "I love driving and working a bulldozer was fun." But towards the end of the move to Cooktown, she developed a lump on her wrist and severe pain in both hands. She assumed the long distance driving was the cause but when the lump and pain persisted, she consulted the local GP.

Ann had suffered from Ross River fever a decade or so earlier and the doctor thought the virus might have returned. When tests discounted this, she wondered if

"I think they were actually relieved that I was no longer able to drive!"

Feisty and as tough as her daughter, Ann's mother was back on her feet within days. On being told about Ann's symptoms and convinced they indicated RA, she urged her to see a specialist.

"She reminded me that my younger brother, one of two sets of twins, had been diagnosed with RA as a child. I'd forgotten but looking back I remembered how much pain he'd been in and how he cried all the time. When he reached adulthood, his RA went away – he was lucky."

What the now 41-year-old didn't realise was

Despite her natural optimism there are times when Ann is unable to fight off despair.

Ann had picked up Dengue fever which also attacks the joints. When this was discounted she admitted being stumped. Telling Ann that there were many conditions in the tropics that the medical profession knew nothing about, she prescribed painkillers.

With no idea what was making her so ill, Ann struggled on but within six months the agonising pain in her hands had spread to her elbows and shoulders. "My joints weren't disfigured and I didn't look like a sick person. Because there were no physical signs that anything was wrong, I know several people dismissed me as a hypochondriac."

Having separated from her husband, Ann had to rely on her sons, Baz and Fred, who were still living at home. They not only had to help get her up in the morning, but had to lift her out of the bath and dress her as well.

"I gave up wearing a bra as there was no way I could do one up. Even pulling a dress over my head became impossible. My shoulders and elbows were so sore that I couldn't lift my arms. I needed help to do the simplest things."

As the pain spread throughout her upper body, it was so unbearable that Ann was no longer able to drive. "When my mother had a heart attack and we rushed to Central Queensland to be with her, Theresa my eldest had to do the driving," says Ann, laughing as she recollected how her kids used to tease her about the number of speeding tickets she collected.

just how rare RA is among Australia's indigenous population. She is extremely proud of her Aboriginal heritage and always describes herself as an Aborigine but as she points out her ancestry, like that of many other Australians, is a hotchpotch of different races.

Referred to a rheumatologist in Cairns, her mother's diagnosis was confirmed and Ann was put on medication to help control the pain and deterioration to her joints. She also explored alternative therapies. "I used to suffer from really bad migraines and when I tried acupuncture, they disappeared. I thought the same thing would happen with my RA but by the time the third needle had been put in, I was screaming," she says.

Next Ann tried an all-natural diet. Then she stopped eating tomatoes. Later she experimented with Chinese herbs. Nothing seemed to help. "Ultimately conventional medications made the difference but finding the right combination took time and with one, my kidneys reacted badly. I threw up and became very ill."

Meeting and falling in love with her current partner has been one of the best things to happen to her. Bill has helped Ann through the bad times and the good. But as she is the first to admit – like many other people with RA – learning to ask for help was difficult.

"I'd always been independent and prided myself on the fact that I'd never had to ask anyone for help. But RA changes everything. I think the hardest part was

not the pain or restricted mobility but accepting that I needed to ask Bill and other people for help.”

No longer able to drive, garden, create leadlights or do many of the things she once loved there are times when Ann, despite her natural optimism, is unable to fight off despair. “The great thing about living in the bush is that you can scream your head off and no one can hear you. Going into the paddock for a good scream is the best therapy and always clears my head. It brings back my sense of perspective.”

Ann says the disease has taught her patience. She still struggles with awful pain and her RA has spread from her upper body to her knees. Although the agony and stiffness of her joints is controlled in part by fortnightly injections, a few days before they are

due the pain she experiences is so excruciating, that she can barely move.

One of her joys these days is being out on the ocean. “I’m a Central Queensland girl so I didn’t know much about the sea but Bill grew up on the ocean and each weekend we take off for our houseboat on the Endeavour River.” The houseboat was a derelict wreck that Bill found and restored. “He even rigged up a special ramp to make it easier for me to climb on board.” The couple also has a dinghy in which they go fishing to catch barramundi, red bream and whatever else nibbles at their lines.

Ann counts her blessings each day. “All my children are healthy and happily married, and I have 11 lovely grandchildren.” Her other blessing she says is her sense of humour. “Once you lose that you’re gone.”

Senator Sue Boyce

Senator for Queensland

“When she is feeling alone, Ann’s sense of humour has helped her to cope with RA.”



I suspect the psychological attitude of someone with RA is very important for managing the disease successfully. Fortunately, the general acceptance and understanding of disability is improving in Australia albeit slowly but in some ways a person is better provided for in the community if their disability is easily visible – if they are in a wheelchair or have Down syndrome for instance.

With RA the disability is hidden. Developing awareness and education will help and as Australia’s population ages and more people come into contact with someone with a disability they may begin to understand better.

I was struck by Ann’s resilience and realistic

attitude. She doesn’t feel sorry for herself and doesn’t think of herself as being disabled either.

Living in Cooktown, a long way from main services and coping with considerable distances to major cities and hospitals, Ann’s laid back attitude has been critical in helping her to overcome any feelings of loneliness or isolation.

Services are very important for people living in rural and remote areas. The lack of qualified health care professionals, even in the cities, is a major cause of concern. If we can get some improvement in metropolitan areas this may enable the expansion of further, better services in rural and remote areas. This is long overdue.

“Driving more than three hours to see me is exhausting for Ann.”



“Rheumatoid arthritis isn’t common among Australia’s indigenous communities and can easily get overlooked by medical officers,” says Cairns rheumatologist Dr David Bossingham. Unlike diabetes and kidney disease, it is not a major indigenous health issue and its symptoms are often confused with those of tropical diseases such as Ross River fever, which is what happened with Ann.

As the nearest rheumatologist to Cooktown each visit to see him in the early years of Ann’s treatment, meant a three-and-a-half hour drive each way on what was then a dirt road. “It was exhausting for her to have to do this,” says Dr Bossingham, who services an area 30 per cent larger than the British Isles.

“There is an appalling lack of rheumatologists in Australia and in Queensland, in particular, and so Ann had no choice and still doesn’t. The only other rheumatologist near to Cairns is in Townsville, 350kms away. The next closest full-time rheumatologist is based at Queensland’s Sunshine Coast.

“There is a rheumatology consultant in Darwin and a specialist in Alice Springs who does some rheumatology, but that’s all there is in the Northern Territory. In north Western Australia there are no full-time rheumatologists to look after patients in Broome, Port Hedland or Derby.”

Dr Bossingham who describes himself as

“somewhat greying, ageing and partly retired”, is extremely concerned about the scarcity of rheumatologists in his state and how many patients such as Ann, are forced to travel hundreds of kilometres to see a specialist and receive treatment.

“One of the problems is funding for rheumatology trainees. This funding comes under the state’s umbrella. Up until recently there was only one funded rheumatology trainee position in Queensland. Now there are five but that still doesn’t address the issue of patient needs or plan for the replacement of baby boomer rheumatologists who are close to retirement or like me, want to retire.

“The desperate need for more rheumatologists, particularly in regional and country areas, must be addressed.” Instead of the emphasis on physician training remaining focused on emergency and in-patient care Dr Bossingham would like to see medical students undertake a period of on-the-job training in consulting rooms where most rheumatology patients are seen.

DR DAVID BOSSINGHAM

**Senior Specialist Physician, Cairns Base Hospital
Associate Professor, University of Queensland, Faculty of Medicine
Adjunct Associate Professor, James Cook University, Faculty of Medicine and Dentistry**

RA is the most serious form of arthritis. There is no cure for RA.



“I thought only old people got RA.
When the doctor told me this was what I had,
I couldn’t stop crying. I cried all the way to work.”

Renee Lang

It hasn’t been easy for 21-year-old Renee Lang to come to terms with having a disease for which there is no cure. She worries that she might have to give up hairdressing a career she loves.

“RA is so unpredictable. I have no idea what the future holds,” she says.

Renee Lang was 18 and had just completed her schooling when she applied for university in her hometown of Adelaide.

“Waiting to hear if I’d been accepted, I took two summer jobs,” she recalls. “One at a hair salon where I helped with shampoos and got clients coffee and tea, the other was at a supermarket as a checkout girl.”

Even as the lowest employee on the totem pole, Renee says she immediately loved hairdressing. For the first time she began to think of it as a possible long-term career. And although she was at everyone’s beck and call and constantly on the move, there were

still moments throughout the day when she could take a break and rest her aching feet.

It was a different story at the supermarket. As a “checkout chick” there was no let up and after standing in one spot for her entire eight-hour shift, Renee would be in such distress because of her feet that she could barely walk.

She had suffered with feet problems since her schooldays and regularly saw a podiatrist and a chiropractor. “When I was 14 and in Year 7, I had a bad back and used to get lots of headaches. The chiropractor told me my neck was out of alignment in some way and the cause of my back pain and

Renee Lang met with Kate Ellis.



headaches. When I began getting pain in my feet, I began seeing a podiatrist. Sometimes my feet were so sore that it would take me a few hours to get going and while I was working at the supermarket the pain worsened considerably. My feet became so swollen that I couldn't get my shoes on."

The podiatrist wasn't able to provide her with any relief and had no idea what was causing the problem. "He was hopeless and said there was nothing he could do for me," says Renee.

Still she persevered. Deciding hairdressing was what she really wanted to do, she successfully

feet, elbow and fingers has largely subsided, she has an on-going fight with fatigue. "If I'm going out on a Saturday night I need to take a nap in the afternoon so I will last the distance. On Saturdays I work at the salon from 8 a.m. until 2 p.m. and without a rest, there's no way I'd be able to keep going until 11 or later at night," she says.

But whether she is in or out of remission, Renee's friends, colleagues and clients find it difficult to understand the effects of RA. They find her constant tiredness and the crippling effects and unrelenting pain that a flare causes bewildering.

"Because I couldn't drink I was always the designated driver...that was so boring."

applied for a job with a top hairdressing salon. With their support she enrolled at a highly-regarded trade school and began her first year as a trainee. But the pain in her feet continued to bother her and became more acute. "My fingers were also swelling up and my left elbow was giving me trouble. My new podiatrist suggested that I should have a blood test."

The result showed Renee had an extremely high rheumatoid factor. Further tests confirmed she had RA. While no one in her immediate family had ever been diagnosed with RA, it was discovered that a great uncle had suffered from the disease.

"I thought that only old people got RA. When the doctor told me this was what I had, I couldn't stop crying. I cried all the way to work."

With treatment Renee experienced some respite from the pain in her feet and fingers but she found it just about impossible to come to terms with the fact she had a disease for which there is no cure. Equally difficult to endure, were the monthly blood tests to monitor the health of her liver and its reactions to the powerful medications, which can sometimes have serious side effects, necessary to control her RA.

"Thinking about it, the back pain I suffered was probably a result of RA," says Renee, who also blames the disease for her on-going struggle with depression which set in during her final year at school.

Now 21 and in her last year of training, she is in remission and although the debilitating pain in her

"Because I look 'normal' they think nothing could be wrong with me," she says. Various boyfriends have frequently become impatient with her lack of energy and inability to impulsively take off somewhere at a short notice or to party into the wee small hours.

Her current boyfriend Cale, an engineering student, is made of different stuff. To help him understand RA, Renee gave him a sheaf of Arthritis Australia fact sheets. "This has opened his eyes," she says. "He went to school with a girl who has RA and he's keen for me to meet her. I'm looking forward to this because only others with RA know what it's really like."

Renee is also friends with a fellow hairdressing trainee who suffers from chronic fatigue syndrome. "We may not share the same disease but we both know what it's like to always be exhausted because of a chronic condition."

Since her diagnosis, Renee has attended Pilates classes once a week and on her physiotherapist's advice, has a remedial massage once a month. The combination of the two has helped loosen up her joints as well as strengthen and loosen her muscles.

As she is now in remission, Renee's medications have also been reduced and for the first time in two years, she is able to enjoy a glass of wine or a beer with her friends. This hadn't been possible since her diagnosis as several of the many medications she was on were not compatible with alcohol. "I wanted to be like every other person my age but because I

couldn't drink whenever I went out with friends, I was always the designated driver which was really boring!"

Although as a hairdresser, Renee is on her feet most of the day and needs dexterity in her fingers, she is determined to make hairdressing her career. "It's good to have a trade and hairdressing is something I can do from home if I have to, setting my own hours and working in my own time. I'd like to be a hairdresser my whole life but if that's not possible, then I'd like to work in aged care.

"My Mum used to do this and I loved going to work with her because it meant being able to talk to older people. I love being with them and I really like hearing about things that happened 30 and 40 years ago."

Despite her optimism, Renee is also a realist. "I

can't tell where I might be in 10 years time or if I'll end up in a wheelchair. I have no idea what the future holds. I'm only 21 and while marriage and children are a long way off, the thought of going off medication during pregnancy scares me. Even in remission, that would terrify me. Then there's caring for the baby. What would happen if I couldn't walk or was in the middle of a flare?"

Even more troubling for Renee is the possibility that she might pass on the rheumatoid factor to her children. "This does really worry me," she admits. But for now, it is something she refuses to dwell on.

Instead she is enjoying being in remission and getting 10 hours sleep a night. In fact, she feels so well that along with Pilates, she has taken up bike riding and horse riding.

The Hon Kate Ellis MP

Minister for Early Childhood Education,
Childcare and Youth and Minister for Sport
Member for Adelaide, South Australia

**"Renee is a wonderful
example of how to
overcome diversity."**



Until I met her I had never met anyone with RA as young as she is, although I knew it was not only an older person's disease. This has been a great opportunity for me to learn about the impact of RA on a young person.

Renee will face some big challenges but I have no doubt she will overcome these and continue to forge ahead in life, refusing to be defined by her disease or letting it interfere with her dreams and ambitions.

Anyone with RA should not be afraid to ask for help whether from friends, colleagues or strangers. I know this is often easier said than done and

understand how people living with rheumatoid arthritis treasure their independence and refuse to see themselves as disabled.

No doubt this difficulty is due to the lack of awareness in the community about RA because it isn't discussed and talked about enough. People with RA should tell the community, their friends and peers what the disease is really like. Better knowledge will make it easier for the next generation of people who will have to live with RA.

I am impressed by Renee's courage and how she has dealt with RA with humour, determination and a complete lack of self pity.

“Once our aim was to control symptoms.
Now it’s to bring about remission.”



“Renee is quite young to have developed RA,” says Dr Jenny Walker. “While there are some cases of women as young as her with the disease the peak age for most women to be diagnosed with RA seems to be when they are in their 30s and 40s.

“The fact that Renee is tenacious and full of vitality, and has a wonderfully supportive family has been important in helping her live with the disease.

“These days when rheumatoid arthritis is diagnosed the policy is to hit it aggressively and early with medication in a bid to bring the disease into remission,” explains Dr Walker who has been following this kind of treatment regime with Renee and has treated her since she was first diagnosed with the disease.

“Currently Renee is in what we call a Low Disease Activity (LDA) state but this doesn’t mean that all symptoms have disappeared or that the disease is totally inactive. True remission in RA is rare,” says Dr Walker. To determine this development, rheumatologists use a tender joint score plus a swollen joint score and a low pain score as measured by the patient.

“Although some people with RA whose disease

is in LDA may continue to suffer from low-grade symptoms such as fatigue or nausea which can be caused by certain medications, the disease itself shows very little activity,” Dr Walker says.

However in some instances by the time there is LDA, some joint damage may have occurred and chronic secondary degenerative arthritis may be a factor in continuing discomfort or pain.

Many people with RA suffer from depression but Dr Walker says that this isn’t all that surprising. “When a disease which can be extremely painful and debilitating hits you in the prime of life and when you are at your most active, it would be hard not to be depressed, particularly when important decisions about such things as career choices and having a family must be made.”

Patients suffering from depression are often put on antidepressant medication and given counselling as well.

DR JENNY WALKER

Consultant Rheumatologist, Flinders Medical Centre

Visiting Rheumatologist, Royal Adelaide Hospital

RA is a chronic condition. It not only affects the person who has it. The impact of the disease on the person’s family is considerable.

“All too often, people with a disability are judged by what they can’t do rather than by what they can. Rheumatoid arthritis has shaped and strengthened me as a person.”

Despina Gonis

For Despina Gonis, a first generation Australian from a traditional, patriarchal Greek family, being diagnosed with RA at 18 was tough enough. But she was forced to take charge of her treatment when her parents who spoke little English couldn’t understand a disease they couldn’t “see”.

When Despina Gonis or Desi as her friends call her, first discovered she had RA it was back in the days when treatments included strapping the affected joint followed by several weeks of complete bed rest.

In times gone by, when the drugs available were pretty ineffective, patients were treated with bed rest to reduce inflammation. Strapping or splints were used on joints to reduce movement and thus pain, and to maintain joints in optimal position.

Admission to hospital for several weeks was standard treatment with a lot of aspirin, splinting, wax baths, heat packs and, sparingly, corticosteroids but not joint injections.

Thirty years later, Desi’s memories are vague about the four weeks she spent as an 18-year-old at Queen Elizabeth Hospital in Adelaide. What she does vividly remember are her fellow patients.

“I was the only young one in the ward. Everyone else was much older. Some were on walkers and others were in wheelchairs,” she says. “From then on, I was convinced that this was my future and that by 40 I’d be in a wheelchair too.

“With me the RA started in my legs but once the anti-inflammatories and medication kicked in, it wasn’t so bad. For the next few years I think I was in some sort of remission.”





Despina Gonis met with Penny Wong.

It was during this time that Desi met Bill at an Adelaide nightclub. "Normally my parents who were very strict would not have let me go but we had a friend from Melbourne staying with us who had never been to a nightclub. So Mum and Dad agreed to let us go if my brother acted as chaperone and we stayed only half an hour."

Thirty minutes isn't much time but that's all it took for Desi to meet Bill and to like what she saw! "He was a first generation Greek like me but his family was not really traditional and they were more Aussie than Greek," she says.

better but two weeks later I collapsed at work. I was unable to walk."

Desi suffered a severe RA flare with pain that was so crippling and joints so swollen she could no longer drive and could barely walk. When her regular rheumatologist returned home he insisted she take four weeks off. "Those four weeks became 13 years. It was that long before I could work again."

For the first 12 months she was unable to drive or walk and sank into a deep depression. "I felt like a prisoner in my own home." Whenever Bill's parents visited, she made an extraordinary effort so

"You have to praise yourself and give yourself credit for what you have accomplished."

The pair began dating but when Bill proposed – not once but twice – Desi turned him down both times and broke off the relationship. "I didn't want to end up as a burden. I was afraid I might pass a degenerative disease on to our children. Bill was persistent. He said he loved the whole person including my RA but he hadn't seen me sick and had only the haziest idea what it meant to have the disease."

Desi's own family was equally confused. "My parents who didn't speak English couldn't understand a disease they couldn't 'see'. When the doctors talked about hip and knee replacements, they asked why I wasn't happy with the body God gave me. They believed doctors were gods. Whatever a doctor told them, they accepted as gospel," she says.

Sharing their attitude to doctors, Desi never questioned her treatments and, at this stage, her RA was largely under control. Two years after they met she and Bill married. Desi was then 25 and until just before her 30th birthday her RA was kept at bay, and didn't interfere with her life at home or her job with a large South Australian company.

Everything changed when her regular rheumatologist went on an overseas trip and she had to see another doctor about pain in her groin. "My GP referred me to a surgeon who didn't seem to understand I had RA. He removed a lymph gland, saying this was the reason for the pain and the swelling. I thought the operation would make me

they wouldn't think their son had married an invalid. She would cook up a storm, give herself a knock-out hairdo, put on her best clothes and lots of make-up and somehow, no matter how terrible she felt would pretend she was "just fine".

Bill tried to be supportive but he found RA frustrating and unpredictable. He didn't fully understand what Desi was going through.

Then the breakthrough that changed Desi's life happened. She was in her early 30s and on a regular visit to the rheumatologist who had taken her on as a patient when her original rheumatologist retired. She found him less caring than her first doctor and felt he was more interested in talking about himself than in treating her.

"When I first went to see him, one of my ankles was strapped up. When I left him a year later, two of my ankles were strapped up as well as both knees! I told him he hadn't helped, was obviously not interested in me or my welfare and that I was leaving and not coming back."

She is still not sure where she found the courage to do this. When she told her Greek GP what she had done he was shocked. But for Desi this was a turning point. "I was a typical Greek girl and so shy. I never spoke unless I was spoken to first. Like my parents, I'd always believed doctors were infallible but, by finally speaking my mind, I felt empowered. At last I was taking charge of my life and standing up for myself."

Her new-found strength influenced every area of Desi's life. She was determined to be a mother and in February 1996, she and Bill were overjoyed when Amelia arrived. Almost immediately Desi experienced a flare. "The pain was excruciating, like having teeth extracted one by one," she says. "It was worth it though to finally become a mother." But this latest flare resulted in her doctor warning that she was in danger of fracturing her hip. He recommended surgery which took place a couple of years later.

She and Bill were keen to have more children but two later pregnancies ended in miscarriage. But there is no shortage of young people in the Gonis household. For the past 11 years, Bill and Desi have been host parents to overseas students in their late

teens from Japan and Germany. "It gives us and Amelia a chance to learn about a world outside our own world," she says.

Desi also holds down a full-time job at the local high school working with children with special needs. Initially she taught Greek cooking but when the physical demands became too much, she was transferred to help children with special needs.

"When you see me, I look as if I am on my last legs but my faculties and my mind are all there," she laughs. "And because I have a disability I understand the children I work with and how like me, they are often judged by what they can't do rather than by what they can.

"You have to praise yourself and give yourself credit for what you have accomplished," she says.

Senator the Hon Penny Wong

Minister for Climate Change and Water
Senator for South Australia

"A member of my family has RA. It's something we've been grappling to understand."

Given this family experience, I do have some understanding of RA. However through meeting Desi, I was given a very personal insight into the daily challenges that people with RA face.

It is difficult to comprehend a disease you can't 'see' particularly when you come from a non-English speaking background. Desi is an extraordinary example of someone who has managed to cope in the face of complicated medical advice and decisions, often on her own.

A person's ethnic background often changes the way they experience the health system and the services provided. Apart from the language barriers



that must be faced if you come from a non-English speaking background, there is a whole range of cultural reasons why this occurs.

It's important to recognise and ensure that the complexities of medical treatment for such people are conveyed in a way that can be easily understood by patients and family members alike. Health messages need to be expressed in simple, uncomplicated language so that they can make informed decisions about their health.

Desi has made me realise just what a lonely disease RA can be and how, without the right support, a person is even more vulnerable.

“RA has transformed Desi from a shy Greek girl into a confident woman.”



Dr Simon Burnet marvels at the way Desi has accepted her RA, managed it and got on with her life.

“Rheumatoid arthritis is more prevalent in women than men and commonly strikes women of child-bearing age,” he says. “When this happens the implications are significant and impact on a woman’s family, on her work and also her relationships.”

People develop RA through no fault of their own. It affects people from all walks of life from the very rich to the very poor. “It’s a terrible disease and what’s amazing is how women like Desi have turned having it into a positive rather than a negative, and how they see the cup as well and truly half full rather than half empty.”

Cultural expectations have a major impact on many patients. Desi admits that when she was younger she felt inhibited by her traditional Greek upbringing and hesitated to speak up for herself. Now she asks questions and wants to be involved every step of the way. “Despite a previous hip replacement and an impending second hip replacement, she continues to set goals for herself at work and personally. She inspires all who meet her,” says Dr Burnet.

These days most people with RA are no longer

prepared to suffer in silence. “They are far better informed than previous generations. Arthritis Australia is an excellent resource and with the advent of the Internet, patients are more prepared to search out information on the disease to learn all they can about the latest treatments and research.”

Doctors also have far more access to information. Dr Burnet says this had led to a greater understanding of the disease and importance of early diagnosis so treatment can begin immediately to bring the disease under control and to prevent joint deformities.

“When Desi was first diagnosed she was admitted to Queen Elizabeth Hospital where bed rest was the conventional treatment. But since that time, treatments have radically changed and today mobility and exercise are encouraged and are strongly recommended as an adjunct to medication.”

DR SIMON BURNET

**Consultant Rheumatologist, Queen Elizabeth Hospital, Adelaide
Medical Director of Arthritis South Australia
Member, Arthritis Australia
Scientific Advisory Committee**

RA is an autoimmune disorder that causes a person’s immune system to start attacking their body’s healthy tissues.



“I virtually crawled from my car to the rheumatologist’s office and even though I was in agony I still hid the truth from her. I believed in a stiff upper lip.”

Sabine Gunton

When Sabine Gunton was diagnosed with RA she was desperate to talk to someone else with the disease. Seven years went by before she did. “My family and friends were terrific but only a person with RA can understand what you’re going through,” she says. “You need to have hope.”

At 45, with three healthy teenage sons, a blissfully happy marriage and a large comfortable home on Sydney’s Northern Beaches, Sabine Gunton and her husband Andrew decided to adopt a child from overseas.

“With our boys all at high school we had room at our table, metaphorically speaking, as well as in our hearts,” she says. “So when good friends of ours adopted a two-year-old from Ethiopia, we were keen to find out more. Over the next few months we met other families who had adopted Ethiopian children and decided this was for us.”

Although born in Germany, Sabine was raised in England. She met Andrew – “the young Australian

guest” – at her best friend’s wedding. “It was mutual love at first sight,” she says.

Married in England where eldest sons Alexander and Jack were born, they moved to Australia where Will was born a short time later. Now 13 years on, once the red tape had been sorted out, Sabine and Andrew planned to fly to Ethiopia to bring Koki, their three-year-old adopted daughter, home.

Without warning, Sabine suddenly began experiencing severe pain in the balls of her feet. Her GP and osteopath thought she must have damaged her feet with unsuitable shoes and suggested she give them a chance to recover by wearing comfortable shoes. As



Sabine Gunton met with Bronwyn Bishop.

Sabine seldom wore anything but foot-friendly flat shoes she disagreed with their diagnosis. She went online, determined to find out what was wrong.

Self-diagnosing herself with either Lyme disease or RA, she asked her GP to give her a blood test. The results revealed Sabine carried the rheumatoid factor. She was sent to a rheumatologist who conducted comprehensive tests that confirmed she had RA.

Athletic, energetic and an enthusiastic horsewoman who had once trained show jumpers and three-day eventers, Sabine was initially unfazed by the diagnosis. "I knew almost nothing about RA and just assumed that with the wonders of modern medicine,

too much pain. If I managed to get down on the floor, I couldn't get up again. One day when the children were having their naps, I burst into tears when I was washing up the dishes in the kitchen. I knew I had to take a break from work and I felt so hopeless."

Most days, driving her car was also impossible. If she sat down, she needed Andrew to lift her and put her back on her feet. Terrified about what was happening to her, she would retreat to the bathroom. "With the shower on, no one could hear me sobbing. I wanted my life back. I couldn't imagine getting better or being pain free. I was in despair and at such a low ebb. I doubted we'd be able to go through with Koki's adoption. How

"Working with children who are terminally ill has really put my condition into perspective."

the pain in my feet would soon be fixed and life would return to normal."

Instead RA invaded every joint in her body which stiffened and became red and swollen. To make matters worse she had a violent reaction to the first medication she was given. Developing a metallic taste in her mouth, all food suddenly became salty and inedible. "The only things that didn't taste awful were milk, white bread and plain pasta, and that's all I ate."

Despite her rheumatologist urging her to persevere with the drug, Sabine was convinced something was seriously wrong. She logged on to the Internet to find out whatever information possible about her medication. Not surprisingly for her age group, Sabine has used the Internet on numerous occasions to learn more about her illness. (Arthritis Australia warns people to be aware of the websites they source and to ensure they are reliable.)

"From my research I concluded that the reason why food tasted so salty was because of an adverse reaction to the drug which had affected my liver. I think it could have ultimately destroyed my liver entirely." She was taken off the drug and her liver suffered no damage.

Shaken by the experience, Sabine searched for another rheumatologist. Her RA was so bad by now that she took one school term off from her job at a childcare centre. "I loved working there but I was in

could I look after her when I couldn't look after myself?"

Sabine was desperate to talk to someone else who had the disease. "Andrew and my family and friends were terrific but no one, not even those dearest to you, can understand what it's like. It was seven years before I met another person with RA. Today we give each other support but back then, when I was at my worst, there was no one."

Sabine plans to set up a local network in her area for others with RA, particularly those who have just been diagnosed. "They will be able to phone me or meet me in person over a cup of coffee if they wish. Above all I want them to know they are not alone and there is hope," she says.

Everything changed for Sabine when she found a new rheumatologist who she trusted and who fully involved her in the treatment of her disease, even going online with her to discuss the latest findings and treatments.

"The biggest mistake I made in the beginning was not being honest with my rheumatologist," she says. "Like many women, I believed in a stiff upper lip. When my doctor asked how I was, I wouldn't let on I was in such intense pain that I'd virtually crawled from my car to her office. Instead I pretended the pain wasn't so bad. I didn't want her to think I was the complaining type."

But eventually the pain became so overwhelming that she was forced to admit the truth. Until then her

rheumatologist had no idea of the severity of her RA or the anguish she was going through. Giving Sabine her first-ever cortisone shot, she promised it would give her some relief. "For the first time in months instead of crawling down the steps to our house backwards because going down that way seemed to hurt less, I skipped down the steps like a normal person."

Several months later, with her medication adjusted and her RA under control, Sabine and Andrew flew to Ethiopia to collect their daughter. Koki is now 11 and is a happy, friendly child.

Sabine's RA still remains largely under control. About the only sign she has of the disease is when she gestures with her hands and it's noticeable that they're twisted and knobby. But as she points out, it's a small price to pay when she can do virtually everything else.

Now 54 and filled with her old energy, Sabine takes the family's Jack Russell dogs, Daisy and Andy, on long walks every day. Last year she and Andrew walked New Zealand's rugged Milford Track, 53kms long and arguably that country's most famous walk. "That was really major," she says proudly.

Sabine is back in the workforce as housekeeper at nearby Bear Cottage, a hospice for terminally-ill children. As well she's studying for a Community Services Work Certificate with the goal of working in paediatric palliative care and recently completed a course for volunteers at Westmead Children's Hospital as a family support person for families caring for terminally-ill children at home. "Working with children who are terminally ill really puts my condition into perspective."

The Hon Bronwyn Bishop MP

Shadow Minister for Seniors
Member for Mackellar, NSW

"No one should hesitate to challenge their primary care provider."



Sabine's persistence at seeking a proper diagnosis and then finding the right specialist – one who suited her and that she trusted – to take over the management of her disease is to be commended. If she hadn't persevered she probably wouldn't be where she is today and further irreversible physical damage to her joints may have occurred.

At the end of the day we are in charge of our bodies and our doctors are there to share their knowledge and experience. They should be encouraged to inform patients of the range of treatments available, what they do and the possible side effects. It's only with this kind of knowledge that patients can comprehend precisely why a certain

treatment will work, the impact it will have on their lives and the side effects they may have to cope with.

I've learned much about arthritis since becoming involved with Arthritis Australia. For instance, there are so many myths associated with arthritis with one of the biggest problems being the inability of most people to distinguish between rheumatoid arthritis and what they call 'arthritis'.

Often the general view is that 'it's only arthritis' without people understanding the many different forms of arthritis or how debilitating and serious RA can be.

Mrs Bishop is a member of Arthritis Australia's Parliamentary Friends of Arthritis.

“Women with RA generally don’t like to complain about the way they are feeling.”



“Walking New Zealand’s rugged Milford Track was a real challenge for Sabine and revealed her determination and refusal to let RA determine how she lives her life,” says Dr Beatrice Janssen.

Nevertheless she admits to being taken aback somewhat to discover that in the first few months of their initial meeting, Sabine hadn’t told her the truth about just how bad she was feeling or how much pain she was in.

“Rheumatologists hope all their patients will be honest with them so we can treat them with the appropriate medications and help them manage their RA. If a patient doesn’t tell me exactly how they are feeling it is difficult to gauge how much pain they might be in,” Dr Janssen explains.

“Some patients may look fine but be in terrible pain while others will have joints that look terrible but may be suffering very little pain or no pain at all. Just like everyone else doctors can’t tell what people with RA are experiencing just by looking. That’s why patients have to be honest with us so we can treat them effectively.”

Dr Janssen has been treating Sabine since 2001 and knows her well. “She is typical of most women with RA who generally don’t like to complain and also refuse to take time off work, or seek help with managing the household and family. They soldier on without realising just how unwell they are.”

Most people with RA are often unaware of quite how bad they are and how severe their symptoms are, Dr Janssen says. “They only understand when they are well again and realise what it is like to be pain free.”

She is encouraged by the way the treatment of RA has forged ahead over the past decade and like her colleagues stresses that early diagnosis and immediate aggressive treatment remains the key to successfully treating the disease.

“When this is done and modern drugs such as biologics are used, RA can be frequently halted in its tracks.”

DR BEATRICE JANSSEN

**Visiting Medical Officer, Rheumatology
Royal North Shore Hospital, Sydney**

Regular physical activity helps to reduce the pain of RA, strengthens muscles, maintains joint functions and improves sleep and overall health.

“I was angry at the world and everyone in it. I could no longer do the things I loved doing and I couldn’t see a future for myself.”

Hayley Foyster

Medication keeps Hayley Foyster going. “I know people think I take too many drugs. They say ‘suck it up, deal with it’ but if they want to have a drink after work to dull the pain of a hard day that’s okay. Their kind of pain doesn’t compare with the pain I endure.”

With her sun-streaked hair, tanned body and trendy tattoos, 34-year-old Hayley Foyster is very much a beach girl, in love with sand, sea and surf.

As a teenager she seemed destined to become a sporting champion. A popular, well-known youngster in her home town of Kingscliff on the north coast of New South Wales, she competed at a state level in swimming and surf events and represented NSW as a member of its Senior Surf Lifesaving Team on its tour of New Zealand in 1993. Life was good. Hayley’s future looked promising.

But by the time she was 18 she had abandoned her dream of becoming an Australian champion.

The pain in her joints had finally become too much, forcing her to give up her sporting ambitions. Hayley was devastated.

Although she had suffered joint pains from the time she was five, Hayley wasn’t diagnosed with juvenile onset rheumatoid arthritis until she was 13. Somehow with sheer determination and amazing courage she had beaten the odds and made a name for herself as a junior athlete even though competing with swollen inflamed joints caused her appalling pain.

Now, just as she was on the verge of making it nationally, her dream was over. In constant pain, confused and desperately unhappy, she became



Hayley Foyster met with Justine Elliot.



profoundly depressed. "I was angry at the world and everyone in it. I could no longer do the things I loved doing and I couldn't see a future for myself."

As solace, Hayley turned to drugs. "I only ever took a bit of speed or pot and only for a short time. I suppose it was my way of rebelling but in the end watching healthy people with good bodies use drugs to trash themselves made me even angrier. So I quit." But her anger remained, much of it directed at those who had failed to diagnose her RA when she first began suffering pain in her knees as a small child.

"Doctors and paediatricians put my joint pains

feed herself. "My older brother, David, would carry me downstairs, take me to the bathroom, dress me and brush my hair," she says. At the same time her depression worsened. She even attempted suicide. "I was in so much pain I didn't want to be alive."

But her mother, Jennifer Priest, refused to let Hayley give up. She'd contacted Laurie Lawrence who knew Hayley from her swimming days and he offered her a job. Every day Jennifer would drive her to Laurie's Swim School which was then at Mudgeeraba, a Gold Coast suburb. Sometimes when Hayley's RA was bad, she carried her daughter from the car to the pool.

"What's important to me are my job and my family – they mean everything to me."

down to growing pains but it was much more than that. When I walked my knees seriously hurt and they'd often lock so I couldn't move at all. It was torture to walk down steps. My knees couldn't deal with the downward pressure. Even if I was just stepping off a kerb, my knees would give way under me and I'd end up in the gutter."

Hayley believes if she had been diagnosed when she was little and given treatment early, she probably would no longer have RA. "That still makes me angry," she admits. At school, she put on a bright face but says that her teachers didn't make her life easy. "They didn't understand how RA can flare up one day and be okay the next. Whenever I had time off they would give me a hard time, convinced I'd waggled school to take part in some swimming event."

During these years Hayley frequently had to wear a leg brace for support and needed cortisone shots in her joints as well as arthroscopic procedures (keyhole surgery) to drain fluid from her knees and wash out the joint. This can provide relief and improvement in walking for a period of time. "I had three on one knee and two on the other," she recalls. She also had arthroscopy on both elbows.

"Things were bearable for awhile but after a few months the treatment became ineffective," she says.

Her RA became increasingly worse. "For a short time I couldn't walk at all. I had to be carried everywhere as I refused to use a wheelchair." By 19 Hayley could no longer walk, brush her own hair or

Lawrence, a sports champion himself and well known as an Olympic and world champion swimming coach, is a powerful motivator. "He and Mum saved my life." Hayley says she will be ever grateful for her mother's devotion and Laurie's offer of a job teaching babies, children and adults how to swim. "Laurie was an unbelievable boss."

She has been teaching swimming for 15 years now. "There are days when I can't walk but after six or so hours in the pool, I can climb out unassisted. Teaching is great fun but swimming is also terrific hydrotherapy," she grins.

While having a job she loved boosted Hayley's self esteem and independence, there were also grim setbacks including a short but tough battle with an addiction to morphine which had been prescribed to deaden pain. There was also an experimental bone marrow transplant which proved unsuccessful plus a brief flirtation with alcohol. Through it all was Hayley's fervent desire to have children.

"Years ago doctors told me that because of the drugs I was on, I'd have no chance of having kids. So when I was 18, I had a slice of my ovaries taken out and frozen thinking perhaps one day it could be used by a surrogate or something," she says.

But nature intervened. Much to her delight, Hayley discovered she was pregnant. Isabella, named after the mother of Hayley's adored grandfather, arrived in 2003. Isabella's father is British. "I loved him with my whole heart," says Hayley. He left her when she was

five weeks' pregnant with their second daughter and now lives back in England. Poppy, named after Hayley's grandfather who she called "Pop" was born in 2007.

"Pop died when I was 13 and I think the stress of losing him really triggered my RA." Hayley says she still misses him and her grandmother enormously. She continues to live at Kingscliff with her mother and her daughters. Laurie Lawrence has moved his swim school to Brisbane but Hayley still teaches swimming six days a week at the same local swim school. "During the day Mum looks after the girls They adore her."

One of the most distressing things to deal with is other people's judgement says Hayley. "Medication keeps me going but I know many people think I take too many drugs. They just don't understand the pain I am in. Some of them say 'suck it up, deal with it' but if they want to come home after work complaining

that they've had a bad day and need a drink to dull the pain of it, that's okay. Their kind of pain doesn't compare with the kind of pain I have to endure."

Her condition is now aggravated by a breathing disorder that sometimes has her panting for breath but Hayley has the heart and mind of the champion she once was. She refuses to let it or RA beat her down.

She admits this takes tremendous willpower and that when the pain gets too much, she once again has suicidal thoughts. "What keeps me going are my job and my family," she says. "My family means everything to me."

In November 2009, Hayley shouted her mother and daughters a trip to Sydney to see the new baby elephant at Taronga Zoo. "We had a wonderful time and laughed non-stop. Mum, Isabella and Poppy make my life special and worthwhile."

The Hon Justine Elliot MP

Minister for Ageing*

Federal Member for Richmond

"Providing support for the emotional side of RA is very important."



After spending some time with Hayley I have gained an appreciation of the challenges that she faces. They are challenges most of us cannot comprehend. The specialist appointments, the hospital admissions and the ongoing pain management are hard to imagine.

Most people who meet her would see only a successful young mother and have little idea of her daily reality. The difficulties she faces would be baulked at by most of us but they have not dented Hayley's determination. Not content to watch from the sidelines, her drive has seen her succeed as a

swimming instructor while raising a young family in the Tweed. She is an inspirational young woman with a force of will beyond her years. Even the best of us need some help and I would like to pay tribute to the support Hayley receives from Arthritis Australia. Their fine work in raising awareness and providing valuable support to people with arthritis is to be commended.

*** Ms Elliot's portfolio includes responsibility for arthritis and musculoskeletal conditions. She is a member of Arthritis Australia's Parliamentary Friends of Arthritis.**

“Being diagnosed early can make all the difference.”



Dr de Jager has been Hayley Forster’s rheumatologist since she was 13 and is full of admiration for the former surf lifesaver and swimming champion. He is also singles out Hayley’s mother, Jenny. “She is fantastic and has been a wonderful support for her daughter right from the start. She always comes with Hayley to appointments,” he says.

Dr de Jager is also impressed with Hayley’s GP. “She trusts him implicitly and over the years has built a strong relationship with him. A good GP is absolutely vital in the treatment of RA and a great help to the specialist.

“I usually see Hayley once every three months. If she is unwell, I see her more often but it is her GP who is her main line of support and that she sees on a regular basis. In between appointments I liaise with him by phone. We discuss how she is doing and what may be needed.”

It concerns Dr de Jager that it was several years after the onset of RA before Hayley was diagnosed, pointing out that early diagnosis is essential for the best outcomes.

“Being diagnosed early can make all the difference. When there is pain in any joint that

persists beyond six weeks, then the joint or joints in question should be carefully looked at and if it turns out the person doesn’t have RA, nothing is lost. But for those who do have RA, the sooner treatment is instigated, the better the outcome will be.”

The delay in Hayley’s diagnosis, he believes, may have been due to the fact that her blood was negative for the rheumatoid factor (an antibody that is measurable in the blood and commonly used as a test for the diagnosis of RA), and the soreness in her joints put down to growing pains which can be common in young women, particularly active ones such as Hayley.

“While the rheumatoid factor can be a guide, it is not definitive. Seventy-five percent of those with RA carry the rheumatoid factor but 25 per cent do not,” he says. “So while carrying out such tests certainly play a part in the diagnosis of RA and can be helpful, they are not conclusive.”

DR JULIEN DE JAGER

**Senior Visiting Rheumatologist
Gold Coast Hospital, Queensland
Member, Arthritis Australia
Scientific Advisory Committee**

RA is more common in females who also tend to develop the disease at a more earlier age than men. It is not known why.



“When you get a disease like RA you can let it beat you or take charge and beat it. Knowledge takes away fear. The more you know about RA, the more empowered you become.”

Judith Nguyen

An identical triplet, Judith Nguyen and her sisters made headlines when they were born in New Zealand. Although the sisters share the same DNA Judith is the only one who developed RA. She believes it was triggered by the stress of having to flee Saigon during the Vietnam War.

Judith Nguyen is a charming woman, elegant and softly spoken. She has battled rheumatoid arthritis for more than 33 years. During this time she has not only had to cope with debilitating and extremely painful flares but undergone six joint replacements, had one of her ankles fused and spent countless nights lying in bed, unable to sleep because of the pain.

But no matter how severe the flares or how desperately ill she has been, the Sydney-based career woman stubbornly refuses to see herself as disabled. “When you get a disease like this, you can let it beat you or take charge and beat it,” she says.

Judith was 30 and the mother of two small

children when she was diagnosed and determined to continue her career as a high school English teacher. She clocked up more than 20 years in education before she switched jobs to become Manager of Corporate Communications for several government departments based in Hobart.

Five years ago when she was 58, Judith retired but has showed no signs of slowing down. She continues to be actively involved with various organisations and is not only a director of Arthritis Australia but works tirelessly in her role as its Consumer Representative. “The best way of dealing with pain is to keep physically and mentally

Judith Nguyen met with Tanya Plibersek.



active," she says. "The pain doesn't stop but by concentrating on something else - such as work - you can deflect the pain and forget about it for a time." However savage the pain though, Judith has always refused to take time off.

"On bad days my husband would help me out of bed, dress me, put on my makeup and earrings and drive me to school. Friends would meet us and get me into the classroom and up on a high stool so I was ready to start the day's lessons.

Judith's husband, Vietnamese-born Professor Thông Nguyen, Emeritus Professor of Electrical

timber underneath," she remembers. A day or two later, she felt pain in the middle finger of her right hand. Then the middle finger of the opposite hand began to hurt, followed by her right then left shoulder. She thought she'd pulled a tendon but on seeking medical advice she was told she had RA.

Interestingly, although Judith is an identical triplet, sharing the same DNA as her sisters, she is the only member of the family to develop RA. Although the causes of RA remain unknown, Judith is interested by one current theory that links the disease to the viruses we all carry, suggesting

"RA has brought our family closer together and strengthened the bonds between us."

Engineering at the University of Tasmania, has been a constant support throughout her long battle with RA. "He's been absolutely marvellous and certainly the mainstay on the domestic front."

One of identical female triplets, Judith grew up in Feilding, New Zealand, and met Thông when she was a 19-year-old arts student at the University of Auckland. Having obtained a first class honours degree in engineering, Thông, a Colombo Plan scholar, was studying for his PhD.

Married in 1968, the couple left for Vietnam the following year and despite the country being at war, Judith enjoyed her new home and her husband's welcoming, loving family. Six years later as Saigon was about to fall, the New Zealand Government issued orders for its nationals to leave. With only two hours' notice, Judith took the children, Sarah and Andrew, and with only the clothes she had on and one small suitcase, boarded a Royal New Zealand Air Force Bristol Freighter for Auckland, leaving her husband and his family behind.

"Because Thông was Vietnamese, it took longer for him to get out," she says, remembering this period of her life as one of great emotional strain. When he did finally make it to New Zealand Thông was immediately appointed a Senior Lecturer in Electrical Engineering at the University of Auckland while Judith resumed secondary school teaching.

"We bought a house and I began stripping the staircase banisters to get to the beautiful kauri

stress as the possible trigger. While the trauma of her escape from Vietnam may not have caused her RA, Judith believes it may well have operated as a trigger and upset her immune system so much that her body began attacking itself.

As well as starting her on treatment to help relieve the pain and prevent deformity of her joints Judith's rheumatologist lent her books so she could find out as much as she could about RA.

"Knowledge takes away fear and the more you know, the more empowered you become," she says, adding that whatever she learned she shared with Thông and the children. "RA impacts the whole family as well as friends and colleagues so it's important they also know what is happening to you and how best they can help."

Sarah and Andrew pitched in by making their own beds and helping out with housework, supermarket shopping and meal preparation. Everything was done as a family. "It brought us even closer together and strengthened the bonds between us.

"You can't expect your loved ones to feel your pain," Judith says. "There's no point in waking up your husband in the middle of the night because you are in pain. There's nothing he can do. What's more important is having him support you in other ways.

"Pain is something you have to go through alone and to cope with it, you need to develop a mental toughness and become self-sufficient. That

doesn't mean you shouldn't ask for help however, but it should be for practical things that will make life easier such as help with meals, shopping or a higher desk at work, or lever handles on doors instead of door knobs which are impossible for someone with RA."

Sarah and Andrew are now adults with children of their own and Judith says her four grandchildren are a constant joy. "When my two were young, I couldn't pick them up for a cuddle or get down on the floor to play because my RA was in its inflammatory stage and the pain was so bad. But I'm now in what's called the secondary degenerative stage, which means my joints are damaged and worn down but no longer inflict the sort of agony they once did."

In the years she's had RA, Judith has lost mobility, flexibility, muscle mass and muscle strength. She undergoes blood tests every six weeks to monitor any adverse reactions or side effects from the powerful medications she is on. Almost incredibly Judith regards herself as one of the 'lucky ones'. "I am," she insists.

"RA is an expensive disease with high cost medications and joint replacement surgery. I've been fortunate enough to be able to afford private medical insurance which I know is not the case for many families. Depression is another big factor with RA but again, that's also where I've been lucky. It hasn't been a part of my illness.

"This doesn't mean however that I don't have moments when I feel sorry for myself."

The Hon Tanya Plibersek MP

Minister for Housing*

Member for Sydney, NSW

"Judith's determination to fully live every minute of every day is impressive."



I knew a little about RA as a close friend of my mother has the disease but Judith has really put RA into perspective for me by answering the questions I would like to ask my mother's friend but never have because they're the sort of things you don't like to ask of people you know.

But until we met I had little conception of the pain and financial cost of RA and I admire Judith's willpower not to let RA stop her from holding down a full-time job and raising two children.

It's good to know that treatments are so much better these days than they were when Judith was diagnosed more than 30 years ago, and that

therefore the prospects of managing RA are more encouraging. I am sure if Judith had been diagnosed in more recent times, it is likely she would not have experienced so much joint damage. Nor would there have been the necessity for so many joint replacements.

But even so, because of early diagnosis, medications and her husband's support Judith has led a fulfilled life and her example would be especially reassuring for people newly diagnosed with RA..

***Ms Plibersek is also Minister for the Status of Women. She is a member of Arthritis Australia's Parliamentary Friends of Arthritis.**

“RA affects relationships. It can be very difficult on a partner or carer.”



“Current evidence shows that a person’s psychological makeup is an important factor in the way they deal with a chronic disease such as RA,” says Dr Neil McGill.

“Some like Judith learn coping skills which enable them to successfully manage stressful situations as well as the stress of having a chronic disease,” he says. “But others may be less able to deal with their illness and may require additional support and sometimes antidepressants to enable them to cope.”

However a patient reacts, RA has a major impact on their lives not only affecting their physical wellbeing and mobility, but also their finances and their relationships both at home and at work.

“RA can be very difficult on a partner or carer, who must also come to terms with the fact that the circumstances have suddenly changed and previously shared experiences may also suddenly differ. This can be difficult to understand and ultimately, to accept.”

Some people have to give up their jobs as a result of RA and, along with the loss of employment, find themselves and their families faced with a host of direct and indirect costs. These include everything from the cost of medication and regular visits to their

GP and rheumatologist, as well as indirect costs for such things as modified footwear or specially-made orthopaedic shoes, aids such as splints, special cutlery or well-designed stools or chairs to make sitting easier and more comfortable.

Indirect costs also include the expense of transport to and from regular doctor’s appointments, parking and for those who still work, docked salaries for time off to see a doctor or specialist or for the number of days they may have to take off to recover from a flare.

“RA does limit a person’s life,” says Dr McGill who admires Judith’s attitude and praises the way she determinedly took up new hobbies and interests after discovering she could no longer garden, play tennis or continue her involvement in other physically active pastimes she used to enjoy.

It intrigues him that although Judith is an identical triplet she is the only one who has contracted RA. “Inheritance is a factor but the other causes of the disease remain unknown.”

DR NEIL W MCGILL

Rheumatologist, Royal Prince

Alfred Hospital, Sydney

Clinical Senior Lecturer, University of Sydney

Advances in RA research now make remission a real possibility. Ten years ago a 20 per cent improvement rate was the goal.

“I didn’t want to be seen as a whinger. With RA no matter how excruciating the pain, you learn to live with it. It’s the fatigue that knocks you rotten.”

Amanda Glynn

When the biologic medication that had kept her RA under control suddenly stopped working 37-year-old Amanda Glynn could no longer walk, drive or dress herself. The timely development of a new biologic gave her back her independence.” It was like a miracle,” she says.

When Amanda Glynn became a mother it was the happiest day of her life. Her son, Jared, arrived in 1996 and for the first three weeks of his life, she was walking on air. She was 26.

Then the pain started. One day it would be in her neck making it agonising to turn around or look up or down. A few days later it had shifted to her wrists. Then her ankles became inflamed and swollen, making walking difficult if not impossible. Next it was her shoulders that seemed to be on fire.

“I only learned later how RA rotates through your whole body,” says Amanda who lives in Perth. “But back then I was hesitant to seek help because I

thought my doctor would think I was a hypochondriac if I went in complaining about my knees and the next week complained about my elbows or my hands. I didn’t want to be seen as a whinger.”

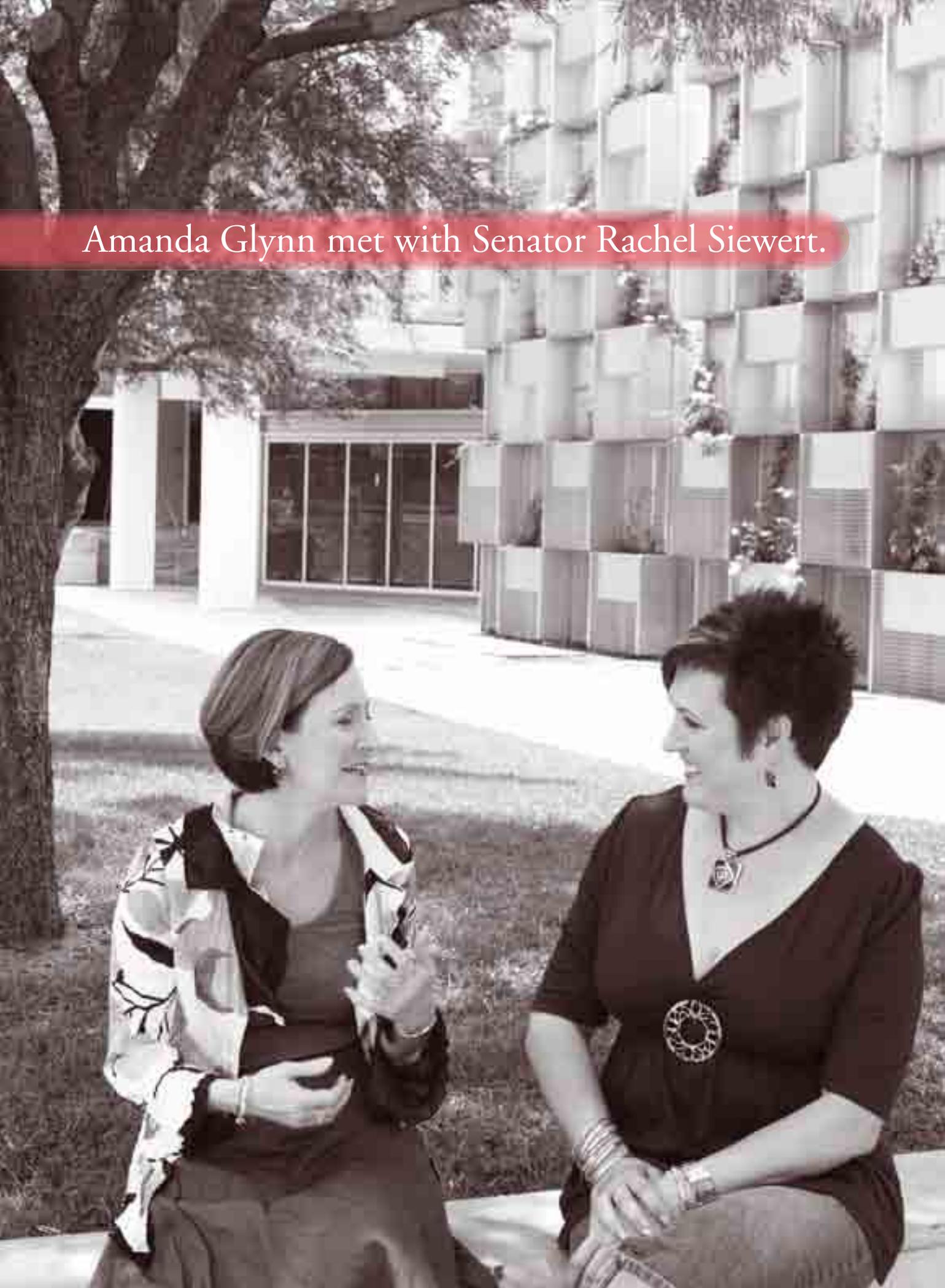
But in the end, the pain became too much and when Jared was two-months-old, Amanda underwent a series of blood tests, scans and MRIs, and discovered she was suffering from pregnancy-induced RA.

“I couldn’t turn taps on or off, take lids off sauce bottles and because my wrists felt as if they were on fire, I had to bundle up Jared with my forearms.”

Stress has long been known to be a factor in RA



Amanda Glynn met with Senator Rachel Siewert.



and Amanda believes the breakdown of her marriage shortly after her son's birth may have contributed to the severity of her condition. Jared was 10 months when she left her husband and went back home to live with her parents for six months. "They were wonderful. Mum took over sterilising Jared's bottles and fitting on the teats which was really difficult for me. Dad would give me massages to help relieve the pain."

Despite her parents' love and care, Amanda missed her independence. She found an apartment 10 minutes away and a job at a postal agency. By working closely with her rheumatologist, her RA was now largely under control.

"I don't want to risk a second pregnancy. It could trigger further problems with RA."

"With RA no matter how excruciating the pain, you learn to live with it," she says. "It's the fatigue that knocks you rotten. You can have a beautiful night's sleep but still wake up feeling like you've been hit by a bus. Some days I'd be so tired that I'd come home from work, look at the breakfast dishes and just want to cry."

A year later, Amanda started a new job at a shoe store only to discover that being on her feet all day caused real problems. She was referred to a foot surgeon who prescribed shoes with specially-made insoles in them. "They're my Nana shoes," she laughs.

Tiredness plus co-workers, who couldn't understand how she could be well one day and not the next, finally became too much for her. She quit her job and was wondering what to do next, when her mother came up with a brilliant idea.

"She suggested I go to beauty school and learn how to become a manicurist so that I could set up my own nail salon at home and work hours that suited me. It was the perfect solution. I was always doing my friends' nails and it was something I loved doing." After obtaining her diploma as a nail technician in 2003, Amanda hit the streets with a bunch of fliers announcing she was open for business.

Another breakthrough came the following year when Amanda's rheumatologist put her on one of the

new biologics. (One of the new class of medicines which target specific chemicals made in the body that are thought to cause inflammation and joint damage.) "It was the answer to a maiden's prayer," she says of the fortnightly injections. "I travelled really well for three years. Then I developed shingles."

Unable to take the biologic as it would counteract the medication needed to cure shingles, Amanda went off all her RA medication and when her shingles disappeared she went back on the biologic again. However, it no longer worked.

No longer able to walk, dress herself or drive, she had to rely on her parents and Jared, who was now 11, for pretty much everything. "My son is an amazing

boy and seemed to know when I needed help without my asking. He'd turn taps on and off for me, help me off the sofa or out of bed and constantly sing out 'I'll get it, Mum'. I'm so proud of him. He is so caring and kind. I'm always being told by others what a well-mannered, awesome kid he is."

Amanda's parents took over cooking and grocery shopping, and once again her father gave her daily massages in an effort to help ease the pain. But one stinking hot summer's night, with Jared gone for the weekend, she reached the end of her tether.

"I had left my painkillers in the kitchen and it took me more than an hour just to get out of bed and along a short passageway to get them. I couldn't stop bawling. My life was falling apart. I rang Mum and Dad who came at once and took me home with them. I sat in their spare room and I cried and cried. The next day they told me I either had to get a carer or move in with them."

Both suggestions filled Amanda with despair. "Although I love my parents I wanted my own life. I was 37. I was too young to be like this."

Luckily, her rheumatologist had good news. She was eligible for a new biologic that had been developed. Due to strict government conditions it was available only to people with RA who had tried every other drug, each of which had to have failed at least twice. "The way that medication worked for me

was some sort of miracle," she says. "Within two weeks, the pain was gone and I was back to being Amanda again!"

To celebrate she had a girls night out with her pals at a local pub which was where she met Barry. "It was October 12, 2007. We clicked instantly and have been together ever since."

Barry has an eight-year-old son, Jacob, and he and Jared who is now 13, get on well together. Very much in love, the couple plan to marry quietly "sometime in the future". Amanda says that while they both love children, they are not planning to have a baby together.

"We have two terrific boys and I don't want to risk a second pregnancy which could trigger further problems with RA. I read in a magazine about a woman with RA who sounded like a mirror image of

me. She had a second baby and after the birth, her RA became so severe that she has been bedridden ever since. I would hate that to happen to me."

For now Amanda's life is filled with positives. Her only complaint is that she can't wear glittering strappy shoes with high heels. "I can put on a pretty dress and get all dolled up for a friend's wedding but no matter how great I want to look, I still have to wear my Nana shoes! If I don't my feet start killing me after 30 minutes or so."

In terms of footwear she is limited to her custom-built shoes and certain types of thongs but that she insists is a small price to pay. Her one big fear is that one day her current medication might, like her earlier biologic, stop working for her RA. "I try not to think about that," she says.

Senator Rachel Siewert

Australian Greens Whip*
Senator for Western Australia

**"Amanda has given me
an insight into the kind of
support a single mum needs."**



People see a few swollen joints and think 'that's arthritis' but, with the new medications, people with RA don't get this kind of disfigurement anymore.

Meeting Amanda re-emphasises the total impact RA can have on a person's life. Most people are sympathetic but when you hear how it impacts on someone's entire life and how it affects the family, it really sinks in. I have also learned that just because you don't look sick, doesn't mean you aren't sick.

With RA you are often dependent on people to care for you and if you don't have a partner, this can mean your parents.

Amanda's parents are great but not being able to see friends or go out and then coping with having a baby, must have been extraordinarily difficult for her. How can someone get on with their life when they are in constant pain?

It's such stressful situation and it's a catch 22 because stress is bad for RA and RA causes stress. That's why emotional support is essential for people living with RA as well as treatments that mitigate the pain and improve mobility.

***Senator Siewert is a member of Arthritis Australia's Parliamentary Friends of Arthritis.**

“RA is not a rare disease. It affects 2.5 per cent of the population.”



Although many people with chronic diseases frequently suffer from depression, Perth rheumatologist, Dr Patrick Hanrahan finds those with RA tend to be optimistic.

“They don’t wallow in their disease and tend not to share the pain or symptoms with friends who mostly have no idea about RA and no real understanding of the pain and fatigue involved.”

Dr Hanrahan, who has been Amanda’s rheumatologist since she was first diagnosed with RA, says the myth of the disease affecting only old people persists. Not only is the general public surprised when they discover someone in their 20s and 30s can suffer from RA, but young people who are diagnosed with RA often are shocked as well.

“The misconception that people grow old and then get RA is still prevalent even among politicians. Few realise how many young people have the disease and how many develop it when – like Amanda – they are in the prime of life,” he says.

RA is not a rare disease he insists, pointing out it affects more 2.5 per cent of the population, which translates to around 520,000 Australians with the disease. Echoing the concern voiced by most

rheumatologists, Dr Hanrahan laments the lack of specialists in country areas and regional towns, as well as inaction by health departments throughout Australia to try and resolve the situation.

“Getting treatment to people in rural and remote areas in a large state like Western Australia is difficult and while Arthritis Australia is very supportive of city rheumatologists who travel to regional centres on a monthly basis, the state government offers little or no support. There are no subsidies for travel, secretarial help or even a clinic where patients can be seen.”

Dr Hanrahan drove to Busselton south west of Perth for more than 15 years on the first Monday of every month and after a long day, would make the three-hour journey back to Perth. Throughout this time, the Western Australia government offered no support and even began charging him for use of a room at the local hospital in which to see patients.

He describes the WA government’s lack of support as short-sighted. “All they did was make treatment for those with arthritis in Busselton more difficult,” he says.

DR PATRICK HANRAHAN

Rheumatologist – Western Australia

It is difficult, and often takes time, to diagnose RA as the symptoms can be similar to other forms of arthritis.

“My doctor says if I lost a little weight it would help but it’s hard to lose weight when you can’t walk any distance and your knees are in bad shape.”

Barbara Dutton

Barbara Dutton was isolated and lonely but refused to let the situation get the better of her. Joining an Arthritis Friendship Group she raises money for arthritis research. “Helping others helps take your mind off yourself,” she says.

Tasmanian Barbara Dutton still remembers the acute pain in her feet that forced her to leave her job as manager of a coffee shop in a bustling department store. “I loved that job and especially mixing with people of all ages from the very young to the very old. But as manager in a service industry, I was never off my feet.

“I tried to continue at the coffee shop for more than two years after I was diagnosed with RA but ultimately I had no choice other than resign. I was no use to anyone. I couldn’t even stand,” she says.

Now 74, Barbara has lived with RA for more than 25 years. The first signs of the disease began

in her feet. “The pain started in my metatarsals, the long bones of my feet,” she says. “I dealt with this by continually changing shoes. I’d take two pairs to work each day and whenever my feet began to hurt I’d switch shoes. In the end though, whatever pair of shoes I put on made little difference. The pain was unbearable and so was walking.”

She never was one for high heels says Barbara. “I only ever wore shoes with low heels or else I wore flats so I knew it wasn’t my footwear that was causing the problem.”

She was sure rest would get rid of the pain. “I thought whatever it was would pass if I put my feet up



Barbara Dutton met with Senator Carol Brown.



at weekends. Instead the pain spread throughout my entire foot, then to my ankles and knees.”

Ultimately it became so bad that even putting her feet to the floor when she got out of bed in the morning was intolerable. “I’d sit on the side of my bed in tears. That’s when I realised I couldn’t take it anymore.”

Her GP in Burnie, where Barbara lived, referred her to a rheumatologist who diagnosed RA and put her on anti-inflammatories. “Thank heavens my

of RA is something many people with the disease have to face. For a single woman it can be particularly difficult.

“At times you feel like pulling the sheet over your head and staying in bed,” says Barbara. “But it’s no good lying around because that simply makes the pain in your joints worse. You stiffen up. So you have to get up and get going.”

One of the ways she fought isolation was to join an Arthritis Friendship Group. “There are about 30 of

“RA is not an easy disease to live with. The medications can be expensive...some people find it a real struggle to make ends meet.”

sister, Lorraine, whose husband was in the navy and overseas at the time, was staying with me. She was very supportive. It was only after I was diagnosed that I became aware that RA runs in our family.

“One of my grandmothers had RA. As a child I had little sympathy for her because she always seemed so crabby. Now that I had RA myself, I understood why she might have been like that. Back then, there wouldn’t have been the drugs that are available today to relieve the pain. She must have suffered terribly. Chronic unrelenting pain can change your personality. I’m sure that’s what happened to my grandmother and why she was so ill-tempered.”

From the outset, Barbara was determined not to end up the same way. She refused to let the pain of RA, the loss of her job and her restricted mobility, change her from someone who was naturally convivial, into a “cranky old woman no one wants to be around”.

Keeping up a brave face wasn’t always easy however. For several years after giving up her job, she desperately missed her colleagues many of whom had become firm friends. She also hated the fact she was no longer independent and instead had to rely on a pension. “I loved the independence my job gave me.”

Eventually Lorraine moved back to her home on the other side of Tasmania, a good hour’s drive or more from Burnie. Isolation and loneliness as a result

us in Burnie and we meet once a month, and have a great time. We range in age from about 40 through to 80. Some of us have RA while others have osteoarthritis.

“We do special trips to the Launceston Casino and enjoy each other’s company on the bus there and back. We also hold special fundraisers such as raffles and bingo nights and collect a fair bit of money for arthritis research.

“I think all of us believe that helping others is a good way to take your mind off yourself.”

Barbara has also become the carer for a long-time family friend who has severe osteoarthritis and has just had open-heart surgery. “He’s 10 times worse than I am. Both his hips have gone and he shuffles about. It’s very sad but I do what I can for him.”

Although Barbara says her pain was appalling for the first 10 years, these days much of the pain has eased. “There were days when I couldn’t even straighten my fingers or walk and while I still have flare ups, in the main my RA is under control.

“But I do need help with some things, such as opening a jar of Vegemite. Fortunately Arthritis Australia has terrific grippers that make opening jars easier. They work really well.”

While Barbara’s pain may be less she now has respiratory problems due to RA. “I have to use a puffer to help me breathe better. My doctor says if I

lost a little weight it would help but it's hard to lose weight when you can't walk any distance and your knees are in bad shape."

Many people don't realise that because RA is an autoimmune disease that it attacks joints as well as internal organs such as the lungs and kidneys as well as the body's blood vessels.

However her RA gives Barbara so little trouble that her trips to Hobart to see her rheumatologist have gone from monthly to two monthly to every six months. She does the journey with Lorraine, who has also developed RA. So far, and much to their relief, there has been no signs of the disease in their other sister or their two brothers.

Barbara and Lorraine make adjacent appointments with their rheumatologist, book into a good hotel for the night and then enjoy a nice dinner

out. "We turn our appointments into an outing," Barbara says. "We talk all the way there and all the way back but, the funny thing is, we never talk about our arthritis. We never dwell on it.

"RA is not an easy disease to live with," she says. "The medications are potent and can be expensive. Being on the aged pension now I have the advantage of bulk billing but for some people it can be really costly especially if they have to take drugs that are not available on the PBS (Pharmaceutical Benefits Scheme). I know some of them find it a real struggle to make ends meet."

Barbara refuses to feel sorry for herself. When asked to sum up what it's like to have RA her reply reflects the attitude so characteristic of her generation. "Well, you can't sit around crying. You have to just get on, don't you?"

Senator Carol Brown

Senator for Tasmania

"Barbara's mental strength combined with her bubbly, bright personality has pulled her through."



Her optimism and positive outlook are typical of people with RA but there are things you don't see, not just physically but emotionally, such as the constant stress of chronic pain, the battle against fatigue and the psychological anguish that goes with all this.

Barbara is a no nonsense woman who doesn't want to bother people about her pain although I'm sure she has had a lot of it over the years. Being forced to leave work early because of her RA must have been difficult but she has got on with her life and is now a carer, and determined to give back to the community by raising funds for arthritis research.

That pretty much sums up Barbara's positive

outlook and attitude. It is clear that being put on one of the biologic drugs about 18 months ago has had huge impact on Barbara's RA, enabling her to do things she hasn't done in years – even mowing the lawn has become much easier.

She is so grateful for being able to access this medication through the Pharmaceutical Benefits Scheme (PBS) and, typical of her personality, seems surprised that such money is being spent on her. What's more, Barbara doesn't even consider that perhaps after all those years of pain, she deserves it.

Senator Brown is a member of Arthritis Australia's Parliamentary Friends of Arthritis.

“RA is a diagnosis I hate making.
It remains a ‘nasty’ disease.”



Graeme Jones has been Barbara’s rheumatologist for many years. Once he used to visit Burnie, where she lives, on a monthly basis.

“But when the flight that used to take me was cancelled, it was no longer feasible,” he says. A return trip by car from Hobart, where he is based, takes more than eight hours. “It’s not so much the time spent driving but the fact that while driving you can do nothing else. The flight took only a short time and I was able to go through patients’ notes and not waste a moment.”

Barbara has had severe disease which has been much better controlled in recent years with new medications. The number of therapies and treatments now available or in development to control and manage RA is something that Professor Jones finds encouraging.

“Barbara has one of the best coping strategies I have ever seen and her great sense of humour helps,” he says.

Like his colleagues, the lack of rheumatologists serving rural and regional Australia, concerns him. Fortunately Barbara and most of his patients have

no problems in making the journey to Hobart once every six months but for many other Australians living in remote or rural areas, he says there is often no access to specialists or treatment without making a journey across vast distances to a centre such as Brisbane, Perth, Sydney or Melbourne.

Professor Jones is also concerned that some doctors are not “up to speed” when it comes to diagnosing or treating RA. “It is not a condition they would have come across during their training.

“These days, rheumatoid arthritis is not something you see in hospitals where most medical training is done. RA is generally treated on an outpatient basis and many GPs have either not seen it or only seen one or two cases, which can present difficulties when it comes to recognising the disease.

“This often results in RA not being diagnosed as early as it should be for the best possible outcomes.”

PROFESSOR GRAEME JONES

**Director of Rheumatology, Royal Hobart Hospital
Head of the Musculoskeletal Unit, Menzies
Research Institute, University of Tasmania
Medical Director Arthritis Australia**

RA is a major cause of disability and
psychological distress with many people
requiring assistance with daily activities.

“Sometimes the pain feels like a truck’s driving over you. I tell myself that I am not going to die from RA and often that’s the only thing that keeps me going.”

Rebecca Henderson

A knockabout country girl, Rebecca Henderson, lived life with zest. She enjoyed her job, played all kinds of sport, often took off for a weekend fishing trip and was content with her lot. But not long after returning from an overseas trip her life changed forever.

Born and bred in Griffith in the Riverina district of New South Wales, Rebecca “Beck” Henderson loved the freedom of living in rural Australia and the strong sense of community in a town, where almost everyone knew each other.

Living in Griffith, in the heart of the lush Murrumbidgee Irrigation Area, with its fragrant citrus orchards and abundant vineyards and wineries was like living in God’s country. Beck was content to stay there for the rest of her life. She looked forward to enjoying whatever lay ahead of her.

Most of her friends were childhood ones. She’d started primary school with them. An athletic

tomboy, she grew up with a brother and string of male cousins who taught her to play rugby league, soccer, touch football and cricket. She was never short of someone to join her on an impromptu fishing trip or weekend bush walk.

She lived at home with her parents and had a great job with the town’s biggest supermarket. “I used to work there after school and once I got my HSC, they took me on full-time,” Beck says. Before long she was promoted to Produce Manager.

At 22, she had been in the workforce for almost five years when she took off for a four-week tour of Europe where she had a ball. “I partied all night and



slept all day.” No sooner had she arrived home when she came down with pneumonia. Four weeks later and back at work, she began to experience awful pain in her wrists. The year was 2001.

“I couldn’t lift anything not even a pen. I thought I must have torn the tendons or a ligament,” she says. Her GP prescribed anti-inflammatories and painkillers but these gave her little relief. The pain quickly spread to her elbows and shoulders as well as fingers, knees and toes.

Putting on a brave face Beck kept on working although it was a constant struggle. “By knock-off

getting in touch with him is never a problem. “He has given me his mobile number and email so I can contact him any time. I trust him completely.”

In addition to seeing her rheumatologist, Beck has monthly blood tests at the local hospital to monitor the health of her kidneys and liver to make sure they are not being affected by any side effects of her powerful medications.

Being diagnosed with RA at 23 is a hard call for any young woman and particularly for someone like Beck who loved the outdoor life. One of the hardest things to accept, she says, is not always being able to

“It was lucky I had private health cover or I’d still be on a waiting list for the operation.”

time I was a mess. I could barely move.” She made countless trips to different GPs but no one could work out what was wrong with her. Her mother, Jenny, a trained nurse and oncology ward sister at Griffith Base Hospital was also at a loss.

“I was given just about every drug under the sun but nothing helped,” she says.

“At one point the doctors thought I might have glandular fever or Ross River fever. Mum briefly wondered if I could have RA but because I was so young and there was no family history of the disease she discounted it.” Beck says.

By now the pain was so bad she could no longer do up her bra, brush her hair or dry herself after her morning shower. One day she was in such misery that her mother rushed her to Emergency at Griffith Base Hospital. Doctors conducted a number of tests and discovered Beck carried the rheumatoid factor.

A referral to a rheumatologist in early 2002 confirmed that Beck had RA. She was put under the care of a Sydney rheumatologist who visits the Riverina once a month. Initially Beck saw him every four weeks and then every three months. Eventually when she was doing well and the medication was working, this dropped to every six months.

“It can be hard to get an appointment when he is in town because everyone wants to see him. Lack of access to specialists is a real drawback to people like me who live in rural towns like Griffith,” she says. But although her rheumatologist is based in Sydney

join in the pranks and fun at parties. About 18 months ago, she tried to defy the odds. At a cousin’s birthday party where everyone was drinking and having a whale of a time, she joined in when a group decided to jump through a window.

“I landed on a pile of bricks, cracked a rib and dislocated my right kneecap,” she says ruefully. At first, her main worry was the cracked rib. “It meant I couldn’t lift anything at work and whenever I sneezed, I would nearly pass out.

“But it was my knee that turned out to be the real problem,” sighs Beck as she remembers the pain. “It swelled up with arthritic fluid and in no time the fluid was throughout my entire leg. My right leg was enormous from my thigh to my ankle and so full of fluid I couldn’t bend it. All I could do was drag it behind me.”

The knee refused to heal and the fluid kept building. When cortisone shots and attempts to drain the fluid under local anaesthetic didn’t work, Beck was flown to Sydney and admitted to St George Private Hospital where she underwent surgery.

“It was lucky I had private health cover or I’d still be on a waiting list for the operation,” Beck says. But even with health insurance, the operation still cost her a hefty \$1700. “That didn’t include Mum’s Sydney hotel bill for the week either.”

Although her right leg is slowly recovering, Beck’s left wrist is now very painful and makes driving difficult. She fears that if the pain becomes persistent she will

Rebecca Henderson met with Kay Hull.



be forced to give up driving, something she doesn't want to contemplate. "That would be too awful."

Amazingly she has seldom missed a day's work. Her job is something she treasures. "I'd have to be half dead before I took time off," she declares defiantly, and then confesses that sometimes the pain feels like "a truck's driving over you".

While she fights against it, Beck's RA sometimes gets the better of her. That's when she hits rock bottom and retreats to her room and locks the door. Ironically, despite there being no RA in their family history, her grandmother, Beryl Bell, has just been diagnosed with the disease.

She is very close to her grandmother. "When we were little and Mum and Dad went to work, they

would drop my brother and me off at Nan's and she'd get us ready for school. We used to go to her place after school as well. I could hardly believe it when Nan started having trouble with her hands and her arms, just like I did.

"Then her RA spread everywhere and got so bad that she hardly do a thing. She couldn't open a jar of jam or even hold her handbag."

These days Beck, who is now 30, is the one who cheers along her grandmother and tries to keep a smile on her face. She drives her to Bingo every week and does whatever she can to help make her life easier.

"I tell Nan that RA is a pain in the butt," says Beck and bursts into laughter. "Actually with RA there is no pain in the butt – just everywhere else!"

Kay Hull MP

The Nationals Chief Whip
Federal Member for Riverina, NSW

"Support services for people living with RA like Beck are inadequate."



The burden of RA seems greater if you live outside of the metropolitan area as Beck does. Cities have a major shortage of support services for those with RA and the problem is compounded in country and regional areas.

There is a shortage of podiatrists and physiotherapists to help them deal with the physical symptoms of the disease and more counsellors are needed to help with the mental anguish and fatigue.

I know someone with severe RA and have some idea of the effort it takes to get out of bed on days when the pain and stiffness is almost too much to bear.

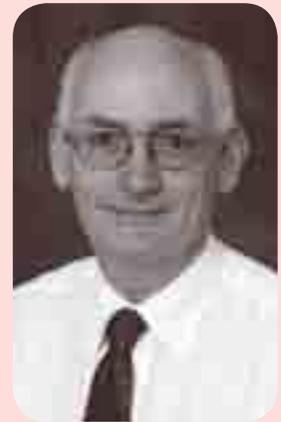
It seems to me that the pain of rheumatoid arthritis is a terribly lonely pain and I know depression is another significant factor.

Anyone diagnosed with RA soon understands that their life will never be the same again. Beck knows this but it's not in her nature to complain. I admire her independence, her work ethic and her gratitude to her parents. She has learned to cope and her determination is impressive.

Meeting Beck has broadened my knowledge about RA. My parliamentary colleagues and I need to lobby and argue for legislation that will support the multidisciplinary care that is required for people with chronic diseases like RA

We need to give them a bright star to see in the future. I am not going to back off from doing this nor will I tire of it. By not giving these people peace of mind, the system has failed.

“County people put up with a lot. They don’t complain as much as they probably should.”



Each month, for the past 15 years Associate Professor Allan Sturgess has visited Griffith in central New South Wales to treat patients in the town and surrounding districts.

So high is the demand that his appointment calendar is constantly booked out. Usually he is able to see his patients once every six months. In the city, he sees most patients every three months.

“Country people put up with a lot. Like Rebecca, they don’t complain nearly as much as they probably should.” Rebecca, Dr Sturgess says, is typical. “She is a strong girl from a family of strong women and is close to her grandmother who was recently diagnosed with RA. She never wants to make a fuss.

“There are few women of Rebecca’s age with RA in the area where she lives which must make it hard for her but like most people from the country she is remarkably stoic. She never calls me about anything trivial.”

What surprises him is how few people in regional and rural Australia are aware of the government subsidies which cover the cost for a patient and a carer to travel to their nearest city to see a specialist and receive urgent or essential treatment. “It’s well known that RA is a huge financial cost to the person

who has it,” says Dr Sturgess, “and associated services should be widely promoted so that those in need will benefit.”

While Griffith Base Hospital arranges everything for Dr Sturgess including patient appointments, his monthly flights from Sydney and his overnight stay, he says that in rural areas this kind of service is the exception rather than the rule.

In an ideal world, Dr Sturgess says state and territory health departments would offer far more support. He would like to see a system introduced where large metropolitan hospitals were linked with regional hospitals to provide monthly clinics staffed by city specialists.

As a way of combating Australia’s lack of rural rheumatologists Dr Sturgess believes that visits to country clinics should be built into the training of all registrars.

“After learning what it is like to practice in the country, maybe these doctors would think about settling there once their training is finished,” he says.

DR ALLAN STURGESS
Associate Professor, Director
Department of Rheumatology
St George Hospital, Sydney

If left untreated RA may lead to damage
to joints that cannot be repaired.

“RA doesn’t just affect the person who has it. It’s a strain on the whole family. I spent three years in a haze. All I could think about was the pain.”

Christine O’Brien

Christine O’Brien still suffers guilt over the years when she was too ill to give her two daughters the mothering and support they needed during adolescence. She feels equally guilty about the burden her illness has put on her husband and the many compromises he has been forced to make.

Despite being a trained nursing sister and working in one of Melbourne’s top hospitals, Christine O’Brien says she knew almost nothing about rheumatoid arthritis. So when she woke up one morning with pain in her joints, she put it down to physical stress.

“I’d been shuffling firewood from a neighbour who had cut down some trees. I’d loaded the car and made six trips back and forth. So when my shoulders and joints started hurting, I just thought I’d overdone it,” she says.

But instead of the pain easing, it increased and within three months had become intolerable. “My knuckles were squishy and swollen, and my fingers

looked like sausages. My feet were just as bad. I felt as if I was walking on two balloons filled with water.”

Referred to a rheumatologist by her GP, she underwent extensive tests and was told she had RA.

The then 35-year-old mother of two had always been full of energy and physically active. She and her husband, Ken, loved to explore the bush where she’d study native plants while he had fun exploring the bugs, spiders and “creepy crawlies”. Riding their tandem bike was another favourite pastime. So was camping.

But now pain crippled her and coping with the couple’s lively pre-schoolers, four-year-old Carolyn and three-year-old Emma, became increasingly



Christine O'Brien met with Jenny Macklin.



difficult. So did the demands of running a household and looking after her hard-working husband. "All I knew about RA when I was diagnosed was that you didn't die from it. I needed to know more. But this was the 1980s. There was no Internet to turn to and when I asked my rheumatologist for more information, he simply looked at me blankly."

Unhappy and in dreadful pain, Christine asked her GP for a referral to another rheumatologist but she found this doctor equally unsatisfactory. When she asked about counselling to help her cope, he gave a dismissive wave and said they'd talk about it at her

too ill to be a wife to Ken or a mother to my girls. I still feel dreadful guilt about that. All I could think about was the pain. If someone had offered to chop off my legs I probably would have let them."

Even pulling the doona back over her after it slipped off during the night became impossible and the pain of getting out of bed in the morning was impossible to bear. "If I managed to get up in time, Carolyn and Emma would dress me but otherwise they were pretty much on their own."

"It wasn't a case of not being there for them – if anything, I was there too much. They'd come home

“Imagine having RA in a developing country with no drugs or support system.”

next appointment which was many weeks away.

"I was stupid. I didn't complain enough. Instead I tried to be brave and carry on as usual." Finally, after more than a year, Christine's flare was brought under control and while she could no longer join Ken on bicycle trips, she was well enough to go on two family camping holidays as well as tend her garden and enrol in cello lessons which had been a long-held dream.

Back in the workforce, she found a job in aged care and although being on her feet all day was a strain she was proud she could once again contribute to the household and, as she puts it, "pull my own weight". But just as Carolyn was preparing to enter high school, Christine's RA took an aggressive turn and developed into a flare that lasted three long painful years.

"With the first flare, my husband initially shut down. But once he got his head around RA, he was a tremendous support. He didn't fuss or mollycoddle me but was very practical which was exactly the approach needed. When the second flare occurred, the first thing he asked was what could he do?"

Ken quickly discovered he had to do practically everything. Forced to quit her job and no longer able to drive, take the kids to school or prepare a meal, Christine was now so disabled she couldn't turn on a tap, let alone peel a potato or hold a knife.

"I spent three years in a haze. I couldn't manage at all. I couldn't think straight. I lost my sense of humour. Nothing could take me out of myself. I was

from school to find me shuffling about in my tracksuit or still in my nightie in a house so messy and out of control that they were too embarrassed to bring their friends home."

Christine's life took a turn for the better when she went to see an occupational therapist and discovered various devices that could make her life easier such as a special chair that enabled her to stand without difficulty and an ergonomic knife that cut by simply applying pressure. She also discovered a whole range of services she could tap into including Arthritis Victoria.

A short time later, she found a rheumatologist who she trusted. "He also listened to me," she says. He told her that while it might take time, they would find a way to bring her current flare under control. "I believed him. He was great and started me on a drug that really helped. He told me that the important thing with RA was to keep adding things to the mix to put the fire out. He has never given up on me. Even when some treatments haven't worked, he keeps on trying."

With her second severe flare finally over, Christine's sense of humour returned and once again she became an involved, loving mother. She also took a new job, this time in retail working in customer service. But the guilt over not being there for her daughters as they became teenagers still haunts her. As does her guilt about the compromises her illness has forced her husband to make.

"Ken has been wonderful. He never complains but

I think it's important he take time out to pursue his own interests. RA doesn't just affect the person who has it. It's a strain on the whole family."

About 18 months ago, after working most of her life, Christine was forced to retire. Although RA flares continue to plague her she retains her positive outlook on life. Shortly before her 59th birthday in November 2009 she had a knee replacement and describes it as "the best birthday present ever".

Over the years, her RA has been relieved by cortisone injections every six months to ease the inflammation and swelling in her thumbs and fingers as well as her knees. The nodules on the inside of her hands were removed in two operations – one in 1995, the other in 1997 – carried out by a plastic surgeon who prevented their re-growth by performing a

tenosynovectomy when he removed the tissue around the tendons from which the nodules grew.

Resourceful and optimistic, Christine is now planning a second knee replacement and although she is no longer able to continue her cello lessons, she has become an active and dedicated member of two Australian native plant societies.

Christine doesn't waste time on self-pity. "So many people are worse off than me. When I watch the hospital drama, RPA, on television and see people coping with terrible things like brain tumours, I realise how lucky I am. I not only have Ken and two tremendous daughters but I live in a fantastic country where you can get the help you need.

"Imagine having RA in a developing country with no drugs or support system."

The Hon Jenny Macklin MP

Minister for Families, Housing,
Community Services & Indigenous Affairs
Member for Heidelberg, Victoria

"Managing pain must be one of the biggest obstacles anyone with RA has to overcome."



I have two friends with the disease and there are times when I can see the pain on one of my friend's faces, and I can see by the way my other friend walks how the pain affects him. It seems to permeate every part of their being and must make it extremely difficult to cope but like my friends, Christine just keeps going.

Given that the pain of RA can be so debilitating, I was taken by how positive Christine is about life. I am also impressed at the way she and Ken manage their relationship because it can't be easy for the partner of someone with RA to cope with the unpredictability of the disease.

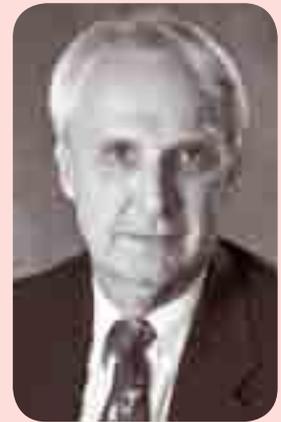
It's good that she has been able to encourage

and accept that Ken should be able to pursue his own interests and have time to himself. Clearly they have a strong relationship. It's obvious Christine also has a strong bond with her rheumatologist who is clearly important to her and instrumental in her on-going treatment.

The reality is a person's RA is not going away and while management of RA is not always perfect I can see that it's essential for people with RA to have a good team around them to give them the support and help they need.

Ms Macklin is a member of Arthritis Australia's Parliamentary Friends of Arthritis.

“There’s no magic bullet for RA and treatment is frequently a matter of trial and error.”



Rheumatoid arthritis impacts on every aspect of a person’s life as well as the lives of their families,” says Associate Professor Russell Buchanan who has treated Christine over many years.

“Christine’s RA has certainly affected her husband and daughters. It wouldn’t have been easy for them to manage all the time. But she shouldn’t feel guilty although I can understand why she might. It would have been hard for her during her children’s adolescence when she was so ill to watch Ken take over the parenting of the girls plus doing the housework as well as caring for her while holding down a full-time job.”

With Christine and his other patients, Dr Buchanan says he always feels “incredibly pleased when I have a win”. But usually what he sees is suffering and those with the disease battling on even though they clearly are having significant difficulties coping with the normal demands of running a home, holding down a job and caring for their children.

“On top of that there is often a limitation of hand function and an inability to carry out simple tasks or hobbies on a day-to-day basis whether this is preparing meals, playing music or using a mouse on a

computer,” he says. “In every way, RA has an effect on the quality of life.”

Like his colleagues he is pleased that treatments have improved greatly over the past decade. “But with RA, there is no magic bullet and treatment is frequently a matter of trial and error,” he says.

Dr Buchanan is encouraged by recent data which strongly suggests that if people are treated aggressively with potent medications in the very early stages of the disease, the impact of RA can be significantly reduced. “Certainly this seems true over the short term. In some cases people even go into remission, but so far these studies have been carried out only in small numbers and further research is needed.”

He says new studies also suggest that a good percentage of children who have been diagnosed with JA (juvenile arthritis) will not grow out of the disease as was once thought. “These studies increasingly recognise the fact that residual symptoms of JA will remain into adulthood and in some cases will continue as an ongoing inflammatory disease.”

ASSOCIATE PROFESSOR RUSSELL BUCHANAN
University of Melbourne, Department of Medicine
Director, Rheumatology Department
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Many people with RA achieve remission which is the goal of treatment.

Can we help you?



For further information, education and support for people with rheumatoid arthritis or any other form of arthritis contact your local State or Territory Arthritis Office

Freecall anywhere in Australia: **1800 011 041**

or visit www.arthritisaustralia.com.au

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Abbott is proud to support Arthritis Australia in bringing the Women's Insights into Rheumatoid Arthritis project to life and sharing the stories of these inspiring women. We remain committed to the discovery and development of new medicines for autoimmune diseases, as well as increasing awareness and education of the impact these diseases have on Australians.



