

CreakyJoints Australia Media Release: 21 February 2020

First Ever Arthritis Patient Guidelines Written For Australian Patients

[CreakyJoints Australia today launched](#) Australia's first patient guidelines for people living with rheumatoid arthritis.

[Raising the Voice of Patients: A Patient's Guide to Living with Rheumatoid Arthritis in Australia](#) is the first guideline of its type to be developed by patients, and reviewed by rheumatologists, specifically for use by Australians living with rheumatoid arthritis and their caregivers. It is designed as a roadmap to help patients navigate their treatment journey and to access the help they need and deserve.

Raising the Voice of Patients is based on the principles outlined in the [CreakyJoints Australia Patient Charter](#) and is the first in a planned series of patient guidelines for Australians with a range of arthritic conditions. There are over 100 different types of arthritis. In Australia, osteoarthritis (caused by injury or wear and tear on the joints) is the most common form, followed by rheumatoid arthritis (RA), a form of inflammatory arthritis.

RA is an autoimmune disease in which the immune system mistakenly triggers inflammation and attacks healthy joints and tissues. This leads to pain, swelling and other symptoms, plus can lead to permanent joint damage without treatment. The symptoms and severity of RA vary widely between individuals, so treatments need to be tailored accordingly.

The total number of Australians with arthritis is projected to rise to 5.4 million by 2030, while nearly half a million currently have rheumatoid arthritis.¹ Three quarters of those diagnosed are female and the average age of onset is between 35-64, often during working age.²

About the new Patient Guidelines

CreakyJoints Australia National Coordinator, Naomi Creek, said, "Patients living with a lifelong, chronic disease need to feel ready and able to take the lead in making decisions about the management of their disease. Understanding what to expect following diagnosis and over the course of their disease is one of the most important aspects of this."

"Our Patient Guidelines for Rheumatoid Arthritis has been written in lay terms to help those at all stages of their disease journey. We are excited to share this free and unique go-to resource with the Australian patient and caregiver community," said Ms Creek.

The inaugural edition of *Raising the Voice of Patients: A Patient's Guide to Living with Rheumatoid Arthritis in Australia* provides:

- Detailed explanations of rheumatoid arthritis symptoms and their causes
- Outlines of current treatment options (including complementary medicines and therapies)
- Practical information about the Australian healthcare system
- Tips for living well with rheumatoid arthritis

Kasey Gardiner, co-author of these patient guidelines and a Queensland representative of the CreakyJoints Australia Patient Council, said, "When you get diagnosed with a chronic disease, your whole reality changes. You're trying to balance doctors' appointments, new medications, and a range of emotions as you come to terms with your new 'normal' and what that could mean."

“Inevitably that search leads you online to learn how other people cope and to gain a better understanding of what you are going through and what lies ahead. These guidelines provide a positive and comprehensive alternative to the misinformation people inevitably encounter online,” said Ms Gardiner.

Rheumatologist Dr Irwin Lim, Director of [BJC Health](#) in Sydney, reviewed these Patient Guidelines prior to publication along with Associate Professor Stephen Hall from Cabrini Medical Centre and Medical Director of [Emeritus Research](#), both in Melbourne.

Dr Lim said, “It’s great to see patient guidelines created with loads of input by actual people who have had to live with the disease. These patients are well-read, experienced, with balanced, considered views, and they’ve produced what looks to be a very useful tool for those grappling to understand RA and the various strategies to manage this disease.”

[*Raising the Voice of Patients: A Patient’s Guide to Living with Rheumatoid Arthritis in Australia*](#) is available for free download. CreakyJoints Australia encourages all healthcare practitioners with RA patients to familiarise themselves with this resource and to share the link creakyjoints.org.au/pg/ with their patients. Free business cards promoting the patient guidelines can be ordered by contacting Ms Creek. Publication of these patient guidelines was made possible by a grant from Eli Lilly Australia.

About CreakyJoints Australia

Founded in 2015, [CreakyJoints Australia](#) is an important source of information for Australian arthritis patients and their families. Our mission is to empower Australians living with arthritis to put themselves at the centre of their own care by talking about their treatment preferences and working in partnership with their healthcare providers.

CreakyJoints Australia connects arthritis patients with current and relevant disease-specific information and support across a spectrum of arthritis conditions, using a diverse set of digital platforms. CreakyJoints Australia provides opportunities for members to proactively advocate for themselves and their families, and to participate in research that will broaden the global understanding of arthritis management.

CreakyJoints Australia is part of the US-based [Global Healthy Living Foundation \(GHLF\)](#), a non-profit organisation whose mission is to improve the quality of life for people with chronic illness.

Sources

¹ Australian Government Department of Health: [National Strategic Action Plan for Arthritis 2019](#)

² Centre for Community-Driven Research: [Rheumatoid Arthritis Australian Study - PEEK Volume 2 Issue 2, April 2019](#)

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