Caring and Arthritis

Practical advice for carers and people living with arthritis.









Arthritis AUSTRALIA

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Practical advice for carers and people living with arthritis.

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The information contained in this booklet is for general information and guidance only. It aims to provide a pathway to access further information and resources for carers and people living with arthritis. Whilst every effort has been made to ensure that the information provided in this booklet is correct and current Home Instead Senior Care cannot accept legal responsibility for any errors or omissions that may have been made.



Introduction

When someone has been diagnosed with arthritis, there can be a lot of factors to consider when thinking about their care. This booklet has been developed by Home Instead Senior Care and Arthritis Australia to help people caring for an adult with arthritis.

This booklet:

- Explains what arthritis is and how it affects people
- Suggests ways a carer can provide practical support
- Provides tips on improving communication between the carer and the person being cared for
- Outlines additional sources of support for people with arthritis
- Includes information about where carers can obtain further advice and support.

Understanding arthritis

What is arthritis?

Arthritis is a name for a group of conditions affecting the joints. There are over 100 forms of arthritis, affecting many different parts of the joint and nearly every joint in the body. Some forms of arthritis can also involve other parts of the body, such as the eyes and skin.

In Australia, nearly one in five people has arthritis. Many people think arthritis is a normal part of growing older. This is not true. Arthritis can affect people from all backgrounds, ages and lifestyles. In fact, two out of every three people with arthritis are aged between 15 and 60 years old.

The most common forms of arthritis are:

- Osteoarthritis
- Rheumatoid arthritis
- Gout
- Ankylosing spondylitis

How is it diagnosed?

It is important arthritis is diagnosed by a doctor (GP or rheumatologist). There are many different types of arthritis, and treatments differ according to the type of arthritis diagnosed. Doctors will use a variety of tests, including physical examination, blood tests and x-rays to diagnose arthritis.

What is the outlook?

Most forms of arthritis run a very uneven course, with variation from day-to-day and from one person to another. The long-term outlook can also be variable and difficult to predict. The majority of arthritis types are long-term (chronic) disorders where the disease can't be cured. For most people, there will be times when symptoms ease but then there will be periods when the symptoms 'flare up' again, often for no clear reason. However, with the right treatment and support, most people with arthritis can learn to cope with their symptoms and lead a full, rewarding life.

For more information and resources about these conditions and other forms of arthritis visit www.arthritisaustralia.com.au



Helping someone with arthritis

Most people with arthritis wish to remain as independent as possible, so finding the right balance between providing support without being overprotective can be a challenge. Stiff joints and muscles can be painful and affect how someone moves, making it difficult for someone to perform their usual activities. Knowing when to offer help or when to stand back can be difficult but will be one of the most important things you can learn.

There are three main ways in which you can help:

1. **Understand what arthritis means.**

   In the same way that understanding their condition helps people with arthritis to cope, the more you understand about arthritis the more you will be able to provide supportive care and assistance.

2. **Support arthritis management.**

   This could range from providing reminders about taking medications, to assisting with recommended exercises, activities or therapies that can be helpful in reducing the symptoms of arthritis.

3. **Communicate effectively.**

   Good communication - listening as well as talking - is essential. It's important that you and the person with arthritis discuss how you're both feeling and agree on how you can work together.

Arthritis symptoms

Arthritis affects different people in different ways, and there is no right or wrong way to feel. A person may experience the following symptoms and/or be affected in the following ways:

Pain

A person with arthritis may experience pain with certain movements or tasks, or it may be constant. It may be worse in the mornings or might build up throughout the day. They may feel pain in a single joint, several joints, muscles, tendons or other soft tissues.

The problem with the pain of arthritis is that it is ongoing. Living with pain can be difficult and make people irritable, angry and, at times, depressed.

Arthritis pain is generally caused by:

- Inflammation
- Damage to the joints
- Muscle tension.

Additionally, pain can be affected by external factors such as stress, fatigue (tiredness) and depression. For example, people who feel depressed or anxious can be more sensitive to pain. They may feel less like doing their usual activities or exercises, leading to further muscle weakness and wasting. This can worsen pain and lead to a continued cycle of fatigue and depression.

How can a carer help?

Look for signs such as:

- Frowning, grimacing or wincing
- Guarding, rubbing or holding a body part
- Difficulty moving or walking differently
- Irritability, anger, aggressiveness
- Becoming withdrawn
- Sleep disturbances, feeling fatigued
- Poor appetite.

Stiffness

Stiff joints and muscles can be painful and make it difficult for a person to perform their usual activities.

Fatigue

Fatigue is often described as exhaustion or a lack of energy. Many people with arthritis experience fatigue, no matter what they have been doing or how much sleep they have had. For some people the tiredness is more difficult to cope with than the pain. There are many possible causes of fatigue, including the disease process itself, pain (which can also affect sleep), certain medications, muscle weakness and wasting, or depression.

Emotional impact

Up to two thirds of people with arthritis say their condition has affected them emotionally:

Fear:	Many people with arthritis are frightened by the impact arthritis is having on their life, and experience fear about what could happen in the future.
Pain:	People living with persistent pain are four times more likely to experience depression or anxiety.
Loss:	Having arthritis can result in a loss of independence, self esteem, the ability to work and continue social or recreational activities. This can lead to feelings of frustration, resentment and isolation.
Stress:	Living with arthritis can place stress on relationships. It can be very difficult for a person with arthritis to watch someone doing something that they saw as their job or having to be helped with tasks that are usually private (for example, toileting and personal hygiene). Pain and tiredness may also make connecting with family members and friends difficult and intimate relationships can also be affected.

"My arthritis makes it difficult for me to cook so it might take me all day to prepare a meal for our whole family on a Sunday, as I need lots of rest breaks. My husband knows it's really important to me to still be able to do that for my family."



Arthritis can make it difficult to carry out normal everyday activities, for example:

Hands: gripping and holding objects, turning taps and keys, dressing.

Knees and hips: getting out of a chair, walking up/down stairs or hills, kneeling or squatting, standing or walking for prolonged periods.

Back: getting out of bed, sitting for prolonged periods, bending down to put on their shoes or socks.

These symptoms may also make hobbies and leisure activities, such as gardening, golf or travelling more difficult.

Arthritis symptoms can also vary from day to day, making tasks that appear easy on some days almost impossible on others. This can make it difficult to predict how much help will be needed. Sometimes you may have to stand back and watch your loved one struggle to achieve a goal that is important to them but don't forget to check in to see if they need help.

"Sometimes the best thing my husband can do for me is to allow me to just complete the task, no matter how long it takes. He knows to respect the struggle."

Managing arthritis

Many of the symptoms of arthritis can be managed, through the right combination of exercise, medications, lifestyle changes and learning to cope. As a carer, you have an important part to play.

Medications

Medications are one of the main treatments for arthritis, which aim to:

- Relieve pain
- Reduce inflammation
- Suppress the immune system
- Reduce joint damage.

How can a carer help?

Encourage the person with arthritis to:

- Understand why the medicine is being taken and what is a reasonable expectation of how effective it will be
- Find out what the possible side effects are
- Read all medication labels and take medications as directed
- Keep a personal record of all medications being taken
- Talk to a doctor or pharmacist before taking any over-the-counter medicines (including complementary or 'natural' medicines)
- Avoid sharing medicines
- Talk to a doctor or pharmacist to answer any questions.

Arthritis Australia's 'Medicines and Arthritis' information sheet.





Diet

No diet or supplement has been proven by research to cure arthritis. The best diet for any type of arthritis is a balanced one to maintain general health and a healthy weight. Being overweight will increase the stress on the joints.

How can a carer help?

Arthritis Australia's 'Healthy Eating and Arthritis' information sheet.

Home Instead Senior Care's Nutrition for Seniors guide shares healthy habits for eating well as you age.

Exercise

Exercise is one of the most important treatments for arthritis and can:

- Reduce pain
- Maintain mobility of joints
- Strengthen muscles
- Improve posture, balance and overall health.

How can a carer help?

Encourage the person with arthritis to:

- Talk to their doctor, physiotherapist or exercise physiologist before starting an exercise program
- Make exercise a daily habit
- Exercise when they have the least amount of pain and stiffness, and when medicines are having the most effect
- Move regularly. Try not to be overprotective and allow the person with arthritis to do as much as they can.

Arthritis Australia's 'Physical Activity' information sheet.

Dealing with pain

There are many different ways to manage pain, so it is worthwhile trying a range of techniques, including:

- Applying heat or cold packs
- Massage
- Acupuncture
- Relaxation techniques
- Distraction techniques (focusing attention on something other than the pain).

How can a carer help?

- Learn to recognise the signs of pain. If the person is having a 'bad day', be patient, provide extra support, and help them to use one of their preferred pain management techniques.

Arthritis Australia's 'Dealing with Pain' information sheet.



Fighting fatigue and joint care

Looking after sore joints during daily activities can help reduce pain, stress and tiredness. It involves:

- Spreading activities throughout the day
- Finding a different way of doing activities that cause pain
- Learning about equipment that can make daily tasks easier
- Seeing an Occupational Therapist (OT) for advice
- Learning strategies and techniques to help get a good night's sleep.

How can a carer help?

- Contact an occupational therapist or an Independent Living Centre for information about aids and adaptations.

Arthritis Australia's 'Fatigue and Arthritis' information sheet and 'At Home with Arthritis' booklet.

Complementary therapies

All treatments, even ones that are classed as natural, can have side effects and interactions. There are many non-medical treatments available, such as vitamin and mineral supplements and herbal medicines. Some of these may work but many are lacking evidence to support their use, have not been shown to be effective and sometimes are not safe. Complementary medications can interact with other medications (eg. prescription medicines) and these interactions can cause serious health problems or make prescribed medication less effective.

How can a carer help?

- Get as much information as possible about the treatment.
- Do not pressure the person with arthritis to try treatments that have not been well proven.
- If the person with arthritis is interested in using complementary therapies, encourage them to discuss them with their GP or rheumatologist.

Arthritis Australia's 'Complementary Therapies' information sheet.

Coping with emotions

It is normal for people with arthritis to experience a wide range of feelings and emotions. Learning to manage negative emotions involves:

- Being aware of, and able to recognise, the signs of stress, depression or other emotions
- Finding someone to talk to – it could be family, friends, children, a support group or online forums
- Seeking help from health professionals if negative emotions are interfering with everyday life
- Learning and practising relaxation techniques, such as meditation, deep breathing, yoga and tai chi
- Staying involved in social activities.

How can a carer help?

- Start the conversation. It can be difficult to know how to help someone who appears to be in need. Choose the right time, indicate that you've noticed a change in their behaviour but let them know you're there to listen without being judgemental.
- Encourage them to focus on positive experiences and think about what they can do rather than things they find difficult.
- Support them to see a health professional if their emotions are too overwhelming to work through alone.
- Try to keep planning social activities and other events they enjoy.

Arthritis Australia's 'Arthritis and Emotional Wellbeing' information sheet.

"Despite my wife's condition and difficulties, her positive attitude has been the most important thing that has helped me as her carer. It has helped her stay healthy and to live as full a life as she can. It has helped me cope with all the changes her arthritis has brought to our lives."

Communicate effectively

Good communication is essential. It is important that you and the person with arthritis are able to discuss how you are both feeling. You need to agree how to work together so that the person will feel able to ask for extra help when needed, and to turn it down when not. Communication is also necessary so that you can judge how they are feeling and respond sensitively.

Here are some tips to help you communicate effectively:

1. **Respect what the person is saying by taking the time to listen and give them your full attention.** To confirm you have understood what the person has said, you may sometimes paraphrase their words back to them as a question. Although you may not understand or agree with them, it is important to recognize and accept that is how they feel.

2. **Pay attention to non-verbal cues as well as what the person is saying.** Learn to recognize the signs of a 'bad day'. Even though the person may be angry or withdrawn, they may actually need extra support at this time.

3. **Consider your own body language.** Show you are listening, by looking at the person, making eye contact and using engaging body language (for example, nodding in agreement).

4. **Consider your choice of words.** Your words can imply emotions and sentiments that you don't actually mean. For example, rather than saying 'Can I make the bed for you', simply say 'Let me make the bed today'.

5. **Be aware of your tone of voice.** Speaking in an angry or exasperated way conveys a far stronger message than the words you're actually saying.

6. **Stay on topic.** Focus on one thing at a time and avoid bringing other issues into the discussion which can escalate a conversation into an argument.

Taking care of the CAREGiver

Caring for someone with arthritis can affect many different aspects of your life as well as theirs. It is important to remember to take care of yourself and your needs as well.

Physical impact

Learning how to safely provide 'hands on' assistance for tasks such as walking, personal care and getting in and out of the car can minimize your risk of injury. Seek advice from a physiotherapist or Occupational Therapist. Independent Living Centres can also recommend equipment and aids to make tasks easier.

It is important to look after your own health and to make time to stay physically active as this will also help to prevent injury. If you do notice pain, weakness or any other signs of an injury, seek advice from a health professional as early as possible.

Emotional/social impact

As a CAREGiver, you may experience stress, anxiety, social isolation or even depression.

Take care of yourself:

- Make time to see family and friends and take part in activities you enjoy.
- Keep in regular contact with a support group or positive friends who understand your challenges.
- Ask for and accept help. Involve family and friends in the care.
- Organise respite or consider the services of a professional CAREGiver.



"Carers need to recognise the importance of having 'you' time. This means dedicating a short period of time each day to yourself."



Planning ahead

It is important to plan ahead for the future. Having an understanding about what resources and services are available to support both you and your loved one can help take the stress out of forward planning.

Whether you suffer from arthritis or are caring for someone, things to consider in the long-term include:

- Home modifications
- Support from and cost of professional CAREGivers
- Your ability to continue with paid work
- What support you may require from your employer to meet the demands of both work and caring
- Early retirement, adequate superannuation, life insurance and other financial concerns.

Services and support

Arthritis is the second leading cause of disability in Australia. If you suffer from or care for someone living with arthritis, there are a variety of care and support services available to help.

Arthritis Australia has a wide range of information resources. Call the free Arthritis Infoline 1800 011 041 or visit arthritisaustralia.com.au. State/Territory Arthritis Offices have information on resources, public seminars and workshops. For more information, please refer to your local office website on the back of this booklet or call 1800 011 041 for more information.

Physiotherapists and Occupational Therapists can advise you on the safest way to provide physical support to someone with arthritis. They will be able to assess your home environment for risks, advise on modifications and the range of assistive equipment available, and teach you how to perform manual tasks safely. Talk to your GP about a referral to your local Community Health Centre, or contact the Australian Physiotherapy Association physiotherapy.asn.au or Occupational Therapy Australia otaus.com.au

Independent Living Centres are located in each capital city and have displays of aids and devices that make daily tasks around the house easier. For advice, including where to purchase equipment, visit ilcaustralia.org.au or call 1300 885 886.

Department of Human Services will be able to determine your eligibility for disability or carer support regarding your income, employment, mobility, travel and other concessions such as a Health Care Card or Medicare rebates. humanservices.gov.au

Department of Health and Ageing has information for consumers, carers and health professionals on resources and government funded arthritis and osteoporosis initiatives. Visit agedcare.health.gov.au

Commonwealth Respite and Carelink Centres (CRCC) provide free and confidential information on local carer support, disability and community services and can link you into short-term, emergency or regular respite care services. Call 1800 052 222 during business hours and 1800 059 059 outside business hours.

Carers Australia provides access for carers to counselling and assistance to manage issues such as stress, loss and grief. Phone 1800 242 636 or visit carersaustralia.com.au

Beyondblue has some fantastic resources and support services for people experiencing mental health challenges to help everyone in Australia achieve their best possible mental health, whatever their age and wherever they live. beyondblue.org.au/who-does-it-affect/olderpeople

My Aged Care website and contact centre can help you understand what programmes and support services are available, determine your eligibility and provide guidance on how to access these programmes. Call 1800 200 422 or visit myagedcare.gov.au

If you are an older person needing support to continue living independently in your own home or you are a younger person living with a disability, you may be eligible for home care and support services such as home help, personal care, home maintenance/modifications, help with shopping, meal preparation, incidental transport, allied health services or respite care for your family carer under the Australian Government Home Care Packages Programme or the Commonwealth Home Support Programme (CHSP).

Home Instead Senior Care's Home Care Solution guide details the various home care options available, eligibility criteria and how to access these services.



About Home Instead Senior Care

Home Instead Senior Care is a specialist, national provider of high-quality in-home care for older people. We help with a range of personal and lifestyle needs while providing welcome companionship. Our services include assistance with personal care, light household duties, meal preparation, medication reminders and transport to appointments, shopping and social outings.

Home Instead CAREGivers are trained to provide assistance to people living with arthritis or other diseases and available to support you from 2 hours up to 24 hours/day, 7 days/week.

For more information visit HOMEINSTEAD.COM.AU or call 1300 008 018 to locate your local Home Instead Senior Care office.

About Arthritis Australia

Arthritis Australia is the peak body representing Australians with arthritis. Our aim is to provide dignity, support and education for Australians suffering from arthritis and their carers; build awareness of the challenges facing people with arthritis and bring quality of life to all people with arthritis and eliminate their suffering. We also fund research into potential causes and possible cures as well as better ways to live with arthritis, and aim to keep primary, allied and community health professionals such as GP's, physiotherapists, occupational therapists, and community nurses informed.

For more information visit arthritisaustralia.com.au or call 1800 011 041.

Appreciation & acknowledgement

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Arthritis AUSTRALIA

Call 1800 011 041

Email: info@arthritisaustralia.com.au

Visit: arthritisaustralia.com.au

Please call our toll-free Arthritis Infoline to be put in touch with your state office for information about arthritis and other musculoskeletal conditions including self-management, community programs, seminars, support groups, resources etc.

The Infoline is staffed by health professionals and specially trained volunteers who are able to answer most questions about living with arthritis.

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arthritis.org.au

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