



Arthritis Ireland
Little Things make a Big Difference

Arthritis Medical Card Submission

What is arthritis?

Arthritis is the single biggest cause of disability in Ireland. It affects almost 1 million people, damaging joints, causing severe pain, stiffness, immobility and deformity. There are over 100 different types of arthritis, the most common of which include osteoarthritis, inflammatory arthritis, juvenile arthritis and fibromyalgia.

- **Osteoarthritis:** This is the wear and tear form of the condition where the cartilage is worn away over time causing pain, stiffness and immobility. It is the most common form of arthritis.
- **Inflammatory Arthritis (including Rheumatoid, Psoriatic, Ankylosing Spondylitis):** This means that a patient's defence system attacks the body's tissues instead of germs, viruses and other foreign substances, causing severe pain, stiffness and joint damage.
- **Juvenile Arthritis (JA):** another form of inflammatory arthritis that affects more than 1,000 children in Ireland
- **Fibromyalgia:** a syndrome that causes widespread pain and stiffness that affects the muscles, ligaments and tendons, but not the joints.

Although arthritis primarily affects the joints it can also inflame and damage the organs, including the eyes, heart and skin.

All types of arthritis can occur at any age (about 165,000 [18%] are under 55) and are chronic, life-long and life-limiting conditions.

There is no cure for any type of arthritis.

Why should people with arthritis be eligible for a medical card?

Many arthritis patients should be entitled to a medical card because the medical and social cost of living with this disease is so great that it significantly reduces a person's finances, and consequently, their quality of life. It is vital that eligibility is decided based on medical and social need, as opposed to the name of the disease as the level of severity of arthritis varies widely. Whatever the type of arthritis is, one patient may have very inactive disease, low medical and social need and not require a medical card, while another patient may have very active disease, very burdensome medical and social need and a medical card for them is essential.

As is outlined in the breakdown and estimated average cost in the sections below, the medical costs of living with arthritis can be vast. They include regular GP and hospital visits, medication to modify the disease, to control inflammation and pain, to counteract vitamin and mineral deficiencies and to manage the side effects of many of these highly toxic treatments. Patients also require regular blood tests to measure medication toxicity and disease activity levels, and they need other therapies, such as physiotherapy, occupational therapy and counselling to manage the physical and emotional impact of the disease.

As well as the medical cost, patients also face a range of other, less obvious but equally burdensome, costs, such as higher heating bills and a need for additional aids and appliances in their homes. Many struggle to engage in activities that others take for granted, for example making a purchase of

groceries or clothing may require delivery – incurring additional charges – because the patient cannot walk more than a few yards at a time and can no longer drive, or a mother who requires additional help to look after her child because she is unable to feed, dress or pick the child up.

The medical and social cost of arthritis is an additional burden on top of the physical and emotional impact of the disease that patients have to live with every day. Arthritis damages joints, causing severe pain, stiffness, immobility and deformity. As mentioned above, this physical impact can prevent people from doing basic, everyday tasks, such as walking, driving, cooking or working. A large proportion of people living with arthritis will also have at least one other disease or condition. According to the Pfizer Health Index, three in ten (29%) people with arthritis also have heart disease. A similar number also suffer from diabetes (32%). There are also links with high cholesterol (20%), high blood pressure (19%) and many others. Osteoporosis, Osteopenia and Sjogrens syndrome are very common co-morbidities of arthritis.

Not surprisingly, therefore, arthritis can cause serious levels of depression and social isolation. According to research conducted by Arthritis Ireland, three in ten patients say they are sad and depressed, and four in ten admit that they sometimes find it hard to keep going and that their arthritis is a constant worry for them. It is unfair to expect arthritis patients to bear the brunt of the medical and social costs when they are already living with the significant physical and emotional impact of the disease.

Arthritis also affects a patient's relationships with their family members, but also the family unit itself, both socially, emotionally and financially. This is particularly true in the case of juvenile arthritis as children are more reliant on their parents and siblings.

If an arthritis patient with high medical and social need is deemed ineligible for a medical card, the consequences can be dire. It is not uncommon for patients to forego their medication and appointments which can lead to permanent joint damage or the development of serious infections. Clearly, this has a serious impact on a patient's daily life as uncontrolled disease will lead to lengthy absence from work and social isolation in their community. In the long-term, the patient will end up more reliant on the health system and state care.

Total estimated average costs of living with arthritis per annum: €5,873

- GP costs @ €500
- Medicines @ €2148
- Other therapies @ €880
- Aids and appliances @ €460
- In-patient treatment & respite care @ €475
- Out-patient treatment @ €1410
- Other costs N/A (Price range varies too widely to give a fair and accurate estimate.)

How do you determine medical card eligibility?

As outlined above, it is imperative that medical card eligibility is not based on the name of a condition, but on the medical and social need of all arthritis patients. To achieve this, patients must be assessed on a case-by-case basis, taking into consideration the physical and emotional impact of the disease, as well as the costs of living with it. Medical and social costs can be assessed by the HSE administration, while a combination of existing assessments can be used to determine the wider impact:

- The **Healthcare Assessment Questionnaire**: measures disability and pain scales across all rheumatic diseases
- A **rheumatology assessment**: a physical examination conducted by a rheumatologist
- A **Rheumatoid Arthritis Impact of Disease (RAID)** questionnaire: Developed by health professionals and patients to provide a clear picture of the broader impact of rheumatoid arthritis on a patient's life, including levels of social isolation and depression, as well as physical factors like pain and fatigue.
- **Psoriatic Arthritis Impact of Disease** questionnaire: Similar to RAID but for patients with psoriatic arthritis.

Similar impact tests must also be developed for osteoarthritis, juvenile arthritis, ankylosing spondylitis and fibromyalgia to measure need in these patients also. Once these assessments are in place, a threshold can be set that patients must exceed for medical card eligibility.

Medical and social costs in detail:

GP costs:

Arthritis accounts for 1 in 3 GP visits in Ireland. Typically a person with arthritis will need to visit their GP once every two months. However, it is not unusual for them to make multiple visits per month as a patient taking immunosuppressant medication to treat their condition is more susceptible to infection. If delayed or left untreated, infections pose a significant threat to a patient's health with a long stay in hospital a likely outcome. Because of this, patients on immunosuppressant medication must have the influenza vaccination annually and the pneumococcal vaccination every five years. These vaccinations are also typically administered by the nurse within the GP practice. A rheumatologist will not prescribe immunosuppressant medication without these vaccinations.

As well as infections, people with arthritis also experience severe episodes of inflammation, known as flare ups, and the GP is the first port of call for treatment with painkillers, Non-Steroidal Anti-Inflammatory Drugs (NSAIDs) and steroids. A flare up can last from days to several weeks and, during this period, patients will need to see their GP at least every week.

Blood tests are also conducted by a GP practice on a monthly basis, a vital part of monitoring the side effects of toxic medical treatments and to measure disease activity, for example a liver function test, platelet levels test or ESR test. Arthritis patients also require their GP for repeat prescriptions.

Estimated GP costs per annum: €500

- 6 blood tests @€30 each
- 4 GP visits @€60 each
- 3 repeat prescriptions @€20 each
- 1 influenza vaccination (cost to administer) @€20

Medicines:

There is no cure for arthritis so patients have to take a whole range of medications to help them to effectively manage it. Most of these medications help to control the symptoms of the disease, while others deal with the more indirect consequences, such as gastrointestinal issues.

Direct:

Most patients are prescribed a combination of **Disease Modifying Anti Rheumatic Drugs (DMARDs), such as methotrexate and biologic therapies**, which are used to alter the underlying disease. Some of the newer biologic therapies are administered by infusion, which adds additional cost to the patient. (Lately, rheumatologists have started to prescribe methotrexate for osteoarthritis patients too.)

Patients will also typically take **NSAIDs** which are used to treat pain and inflammation and are usually taken in addition to the DMARDs. These come in tablet and topical ointment form.

Oral steroids are also an effective medication in arthritis. Some people take low doses every day but most take them in response to a high level of disease activity, such as a flare up.

Steroid injections are also used to stem inflammation and are administered into inflamed joints.

Painkillers are often used to manage pain associated with the disease. These include **paracetamol, codeine** and, when pain is extreme, **opiates** are used.

Vitamin B12 injections are used to counteract deficiency of this vitamin, brought on by arthritis.

People with arthritis are often diagnosed with uveitis or Sjogren's syndrome and require **prescription eye drops**

Mouth ulcers are also caused by arthritis and **mouthwashes**, such as BXT, are required for treatment. **Mouth drops** are also necessary for people with Sjogren's syndrome, who experience a dry mouth.

Indirect:

Arthritis patients on a combination of DMARDs, NSAIDs or steroids will almost always take **gastro-resistant** medication.

Folic acid is required with methotrexate to counteract the loss of this essential vitamin and reduce extreme side effects.

Antihistamines are used to counteract the localised swelling or rash caused by injections.

Antibiotics are used to treat bacterial infections caused by a suppressed immune system.

Anti-depressants are used to treat low mood and depression, a common co-morbidity of arthritis. They are also used to treat the symptoms of fibromyalgia.

Anti-epileptic medication and Selective Serotonin Reuptake Inhibitors (SSRIs) are used in the treatment of fibromyalgia also.

Anti-nausea tablets are often used to counteract the extreme side effects of DMARDs, in particular methotrexate.

Anaesthetic cream is often used on children with juvenile arthritis because of the pain caused by the number of injections they have.

In psoriatic arthritis, **topical ointments** are used to treat the skin rash associated with the condition.

A wide range of **vitamins and minerals** are also taken to boost the body's immune system and counteract medication side effects. These include **vitamin D, iron, calcium and omega 3s**.

Estimated medication costs per annum: €2148

- Drugs Payment Scheme @€144 per month (this covers all of the costs listed above, excluding supplementary vitamins and minerals)
- Supplementary vitamins and minerals @€35 per month

Other Therapies:

Physical therapies are also essential in the treatment of arthritis. Patients often require this treatment immediately. Unfortunately long waiting lists mean that people cannot afford to wait around to be seen via the public system and they are forced to pay for private treatment.

A patient requires **physiotherapy** to maintain their strength and movement of the joints and muscles affected by arthritis. They will typically need to see a physiotherapist 12 times a year.

A patient requires **occupational therapy** to help with day-to-day tasks by providing advice on equipment that can aid a patient with independent living. They also fit a patient for splints for hands, wrists, elbows and neck etc and advise on adaptations to a home. They will typically need to see an occupational therapist twice a year, however children living with juvenile arthritis may need to see them on a more regular basis to help them reach their milestones and for educational requirements. Children with juvenile arthritis will need to have their splints remade by an occupational therapist around twice a year as they grow.

Dentistry is also an essential treatment for patients on biologic therapies to reduce the risk of infection and septicaemia. A patient also needs treatment before and after any surgery.

A patient requires **podiatry and chiropody** to help with ankle and foot problems. These visits can vary from every six weeks to three months.

A patient requires **counselling and psychology** to help with the emotional or psychological impact of the disease. These visits can vary depending on the patient as some will require a short course while others need ongoing treatment. A typical appointment will cost €60.

A patient requires **hydrotherapy** to exercise the joints and muscles while being supported by warm water. The warm temperature of the water aids muscle relaxation and eases pain in the joints. These are usually delivered over a course of 6-8 weeks on an annual basis, costing €250.

Many patients also make use of **complementary therapies**. These include **acupuncture, osteopathy, reflexology and massage** etc. Again, the frequency of use of these may vary considerably depending on the patient. A typical cost here is €60-€80.

Estimated other therapies costs per annum: €880

- Physiotherapy @€65 per visit (8 visits)
- Occupational therapy @€60 per visit (2 visits)
- Dentistry @€50 per visit (2 visits)
- Complementary therapy @ €70 (2 visits)

**This cost is indicative of a treatment plan to maintain a patient's well-being. However, when a patient experiences a high level of disease activity, these costs increase dramatically.*

Aids & Appliances:

An arthritis patient requires physical equipment, known as aids and appliances, in order to live independently. These are worn by a patient, installed in their house and used for mobility purposes. They can vary widely depending on the patient. Below is a list of the most commonly used aids and appliances and an estimated cost of each.

Worn:

Mouthguard (for people with arthritis in their jaw) €120

Splints to support and rest inflamed joints to prevent damage €80 each (numerous required)

Compression clothing for warmth and to increase circulation €30

Orthotics for support and protection for feet €250

Heat packs and icepacks to ease pain and inflammation €30

Sun cream as DMARD medication puts the skin at increased risk of cancer €180

Household:

Electric toothbrush €70

Electric can opener/jar openers €20

Food processor €90

Ergonomic cooking equipment, such as knives, pots and pans

Grab rails for staircases, bathrooms and building entrances €25

Orthopaedic pillow €60

Mobility:

Walking stick/crutches/knee scooter/walking frame €30-€350

Vehicle adaptations such as a car seat swivel or handy bar €40

Estimated aids and appliances costs per annum: €460

- Total cost calculated based on the average price of the items listed above (€70) times the estimated number of purchases per annum (4), plus the annual cost of sun cream.

In-Patient Treatments & Respite Care:

Arthritis patients may be admitted for in-patient treatment for a variety of reasons, the most common of which are high disease activity, like a severe flare up, and infection. This is normally carried out under the care of a rheumatologist and their team.

Aggressive treatment in hospital is often required when a patient experiences high levels of disease activity, such as **steroid infusions** and high doses of **pain relief medication**. Inpatient care can take up to two weeks to get the disease under control and patients will undergo numerous tests to measure the activity during this period.

Children living with juvenile arthritis would frequently receive **steroid injections** under general anaesthetic also, although adults can also be admitted to hospital for these. For example, a patient may receive a steroid epidural into the lumbar region.

In addition to this, patients will often receive **intensive physiotherapy** and **occupational therapy**. This allows them to regain a level of mobility where they can function in everyday life. Further intensive treatment within the community will be required upon discharge.

As mentioned earlier, patients with arthritis are more susceptible to infection because their immune system is compromised by the disease and treatment. An arthritis patient with an infection is susceptible to rapid deterioration in their condition. Quite often a standard dose of **antibiotics** isn't sufficient so it is vital that they get the appropriate treatment as quickly as possible. For example, if a patient develops pneumonia, they will require **oxygen**, and **strong antibiotics and steroids by infusion** so it reaches the blood system quickly. When a patient is experiencing an infection they are unable to take their DMARD/biologic treatment, leaving their arthritis untreated.

Surgery is also a common inpatient treatment in arthritis. It ranges from small procedures, such as operations to remove cysts or nodules, to major surgery, including total joint replacement. Joint replacements are often necessary for people who did not have access to the contemporary DMARD treatments over the years. It is also required for people who have high levels of disease activity, causing permanent joint damage. Other procedures include **resurfacing** the joint, a **synovectomy** to remove the inflamed lining of a joint and **joint fusions, osteotomy** and **carpel tunnel**. Revision surgery is often required later.

Following many forms of inpatient treatment, including surgery and flare management, patients will undergo **rehabilitation**. This can last from a week to several weeks when patients have access to a full programme of therapies, including physiotherapy, hydrotherapy, psychology, occupational therapy and self-management. They will also have access to a rheumatologist and rheumatology nurse specialist. However, waiting lists for rehabilitation can be long, prompting many patients to seek out a private alternative. Post-surgery, patients will also be reliant on mobility devices, for example a scooter or mobility frame, which can be costly.

Estimated in-patient treatment cost per annum: €475

- Hospital treatment @ €75 per day (capped at €750) (5 visits)
- Cost of admission via accident & emergency department @ €100

Out-Patient Treatments:

People with arthritis require out-patient treatments on a regular basis. Although free on the public system, unfortunately many of the treatments listed below have extremely long waiting lists so patients are forced to pay for private treatment to preserve their health. Also, even patients who receive treatment on the public system usually have to top this up with additional private care. Private health care can cover some of these costs, but the excess is still significant.

A **rheumatology appointment** is necessary for many arthritis patients, particularly for inflammatory arthritis, juvenile arthritis and fibromyalgia, on an ongoing basis. According to the Treat to Target recommendations (developed by an international taskforce to inform rheumatologists, healthcare professionals and patients about strategies to reach optimal outcomes for inflammatory arthritis), patients with moderate to high disease activity will visit a rheumatologist every 1-3 months and, once under control, their disease needs to be accessed every 3-6 months. A rheumatologist will typically assess disease activity and create or adjust a treatment plan.

The **orthopaedic department** is also a frequent port of call for patients, particularly people with osteoarthritis, where damaged joints are assessed for replacement. Typically these occur twice prior to surgery and at least once post-op.

Orthopaedics, as well as rheumatology teams, are also responsible for scans, such as x-rays, MRIs and DXA scans to assess joint damage. Treat to Target recommend that x-rays and MRIs take place every year for inflammatory arthritis, while the American College of Rheumatology recommends a DXA scan every 2 years.

Other outpatient treatments include **physiotherapy, occupational therapy, blood and liver tests and ophthalmology**. Children with juvenile arthritis need to be assessed for uveitis at least every six months as they are at a high risk of developing this severe eye condition which often has no symptoms. Intense physiotherapy for children with hypermobility is needed on an ongoing basis to prevent dislocations.

Estimated private out-patient treatment cost per annum: €1,410

- 4 rheumatology/orthopaedic appointments @ €175 each
- 2 MRI scan @ €225 each

- 1 DXA scan @ €100 each
- 2 blood tests @ €80 each
- Therapies such as physiotherapy, occupational therapy etc, costed in Other Therapies above

Other costs & relevant information:

When a person has arthritis, everyday tasks, such as cleaning, cooking, child-minding, shopping or any other manual physical activity, can become painful, arduous struggles with which they need help. As a result, **homecare or assistance** is required to help patients lead as normal a life as possible. This is an additional, non-medical major expense that is not usually available with a medical card. Increased life assurance, health and travel insurance costs are also experienced by people with arthritis.

A patient's finances also have an impact on their **medical adherence**. According to a survey of 310 patients, conducted by Arthritis Ireland, 21% said they had skipped taking their DMARD (biologic) treatment for financial reasons. Patients are also more likely to miss blood tests for the same reasons. This clearly represents a significant threat to patients' health, putting them at risk of long term, irreversible damage. As outlined above, the cost of treatment is significant, in addition to all the other, non-medical costs associated with the disease. This cost, even for those earning a good wage or salary, places a heavy burden on their finances and reduces the monetary benefit of employment.

Work is proven to be good for your health and it is important to people with arthritis, both financially and for their quality of life and wellbeing. It is, therefore, essential that arthritis patients are encouraged to remain in work or return to work when they are well enough to do so. With this in mind, **it is essential that eligibility for the medical card is not decided based on employment.**

Parents of children with juvenile arthritis (JA) are often required to take unpaid leave from work, sometimes up to four times a month, due to the high frequency of their medical appointments. Often one parent in a family will be forced to give up employment to look after their child, placing further financial pressure and emotional stress on the family. It is also not uncommon that children have to miss out on normal childhood activities as the parents must prioritise where their money is spent.

A medical card further eases the financial burden on arthritis patients by reducing the amount they have to pay for the **Universal Social Charge (USC)**. This is important as it frees up additional income to cover costs of items not covered by the medical card, such as suncream, increased heating costs and ergonomic kitchen utensils.

Estimated other costs per annum: N/A

Price range varies too widely to give a fair and accurate estimate

Conclusion

Arthritis accounts for a whole range of diseases that affect people in many different ways. One patient can have mild osteoarthritis, while another has severe inflammatory arthritis. Another may have very severe osteoarthritis, while somebody else has mild inflammatory arthritis. Therefore, it is

essential that medical card eligibility be assessed on medical and social need rather than the name of the condition.

As outlined in detail throughout this submission, the medical and social need of living with arthritis places many patients under a great financial burden. The costs vary widely in nature, from GP visits, medicines and therapies to other necessary outlays, such as appliances and homecare. Although the medical card will not eliminate the financial burden for a person with arthritis, it does go a long way to ensure that they have a better quality of life.

It is also important to note that arthritis patients are already carrying a far greater burden than the average person due to the physical and emotional impact of arthritis. Every day they have to manage the pain and fatigue associated with the disease and also cope with the constant worry, depression and social isolation that is associated with it. As a society, it is unfair to place people who are already living with a chronic, life-long and life-limiting condition under further financial strain. In the end, it only serves to make it harder for people to manage their condition and live their lives. It means they become sicker, less independent and, ultimately, more reliant on the health system and state care.

To determine eligibility for the medical card, patients must be assessed on a case-by-case basis. The medical and social cost can be assessed by the HSE, while the physical and emotional impact can be gauged with a combination of assessments, such as the HAQ, RAID and a rheumatology assessment. Additional, similar assessments must be developed to cover ankylosing spondylitis, juvenile arthritis and fibromyalgia.