


THE CASE FOR SELF-MANAGEMENT

An Arthritis Ireland Report on
7 Years of Positive Patient Outcomes

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A photograph of a person's lower half, wearing a skirt with horizontal stripes in shades of orange, pink, and white. They are walking barefoot on a lush green grassy field. The background is slightly blurred, showing more of the field and a hint of a horizon under a soft sky.

Arthritis Ireland exists to improve the lives of people living with arthritis. Our key goal is to help people self-manage whilst we find a cure to remove the pain and social isolation caused by the disease and ensure people remain active and doing the things they love.

The term '**arthritis**' refers to a whole series of chronic conditions that affect 1 in 5 people in the population, from newborn babies right through to the elderly. Little things, like exercising regularly, eating a balanced diet, planning time and sharing experiences and frustrations about arthritis, can really help a person keep on top of their condition.

The provision of *Living Well with Arthritis* Self-Management Programmes is funded by the HSE and funds raised through the Arthritis Ireland branch network.

Arthritis Ireland would like to express our deep gratitude to our extensive network of Course Leaders who have been delivering courses since 2006 with commitment and passion.

Executive summary

The health of the Irish people and its health system are facing a significant challenge from the rising tide of chronic conditions such as arthritis, diabetes and heart disease. It is the consequence of a number of factors including an ageing population and increasing obesity levels. Already 1 in 3 people are living with a chronic illness in Ireland and this proportion will continue to grow in the years ahead.

Despite great advancements in medications in recent decades, the healthcare system has come under unprecedented strain as it saddles the burden of major budgetary cutbacks coupled with this growing pandemic.

Taking arthritis as an example, high-tech biologic treatments have been extremely effective in stopping joint damage in its tracks but - as no cure exists - patients still need to manage their own condition outside of the clinical setting and the impact it has on their lives such as pain, fatigue, social isolation and loss of employment.

This is where the Arthritis Self Management Programme – delivered nationwide by Arthritis Ireland over the last 7 years

- makes a big difference. By complementing clinical treatment with education and training in problem solving and action planning, it enables and empowers patients to live happier, healthier lives.

The evidence demonstrating the efficacy of this initiative is resounding both nationally and internationally. In a 3 year evaluation of the Arthritis Ireland course (*Living Well with Arthritis*) - which 3,500 people have completed through more than 200 courses - the results show a significant improvement in ability to cope with pain, fatigue and general ability to live with the condition.

Furthermore, there is conclusive evidence to demonstrate that this programme reduces healthcare utilisation, including visits to GPs and hospitals.

According to one study conducted in the US, taking \$1,000 as an average cost per hospital day and \$100 for an average cost of emergency department visit, the expected savings would be \$990 per course participant in the first year.

There is no doubt that self management does work but in order to tackle rising levels of chronic illness, its true potential must be realised.

The following key recommendations require implementation if this is to occur:

- Recognise that self-management programmes are a core clinical priority and be embedded into National Clinical Programmes for all chronic diseases.
- Provide education and training to clinicians and healthcare professionals so that they develop a comprehensive understanding of the self management ethos and can promote it amongst their patients.
- Recognise the vital role the voluntary sector plays in delivering self-management programmes in a community setting.

7 years of the Living Well with Arthritis course:

**+ 3,500 participants + 200 courses
= significant improvements in ability to cope with pain, fatigue and general ability to live with the condition.**



"The key for me was the knowledge I gained."

David O'Mahony

“When I was diagnosed with fibromyalgia I found I had a lot of pain in my shoulders and I also had a problem with fatigue. I'd be sitting down and I wouldn't have an ounce of energy to do anything. It affected my social life in that I had to give up playing golf. At that time the only treatment I had was medication prescribed by the doctor.

Then one day I saw an ad for Arthritis Ireland's Living Well with Arthritis self-management course. That really was when the door opened to the help that is available out there but also and even more importantly what I could do to help myself.

The key for me was the knowledge I gained; that there is something I could do about fibromyalgia. When the pain gets bad instead of sitting around saying woe is me, I try to keep a routine. It teaches you to break the pain cycle and a key part of that is exercise, but also balancing activity with rest.

Now I try to get out for a walk every day but I will also make time to take a rest and listen to music. It's two years since I completed the Living Well with Arthritis course but I still meet the group I did it with once a month. It's a social get together but it gives everyone in the group great encouragement to keep practicing what we learnt.”

Age

75

Occupation

Retired (Sales Rep)

Type of Arthritis

Fibromyalgia,
diagnosed two and a
half years ago

Self-management: meeting the rising tide of chronic conditions

80% to 90% of all care for people with chronic conditions is undertaken by people themselves and their families.

Ireland's population is healthier now than at any stage in its history. Better treatment and prevention has reduced mortality from the major diseases. However chronic health conditions such as arthritis, heart disease, stroke, cancer, and diabetes are on the rise due to an ageing population and with increasing levels of obesity.

Over a third of our population are living with chronic conditions.

In the future, we can expect the burden of conditions to rise because our population will grow, people will live longer and some risk factors such as obesity will become more common. We know too that people living with one condition are often very likely to have experienced another too¹ and the likelihood of developing comorbid or coexisting conditions increases with age.

Unless we address this growing burden we may continue to add more years to our lives without adding more life to those years. These conditions cause significant morbidity and mortality, and result in poorer quality of life for many Irish people.

So, an increasing number of people are living with long-term health conditions which they manage most of the time by themselves.

In fact 80% to 90% of all care for people with chronic conditions is undertaken by people themselves and their families². Helping people to better care for themselves can improve their physical and mental wellbeing and change how they use services.

We live 'longer but sicker' as chronic conditions rise

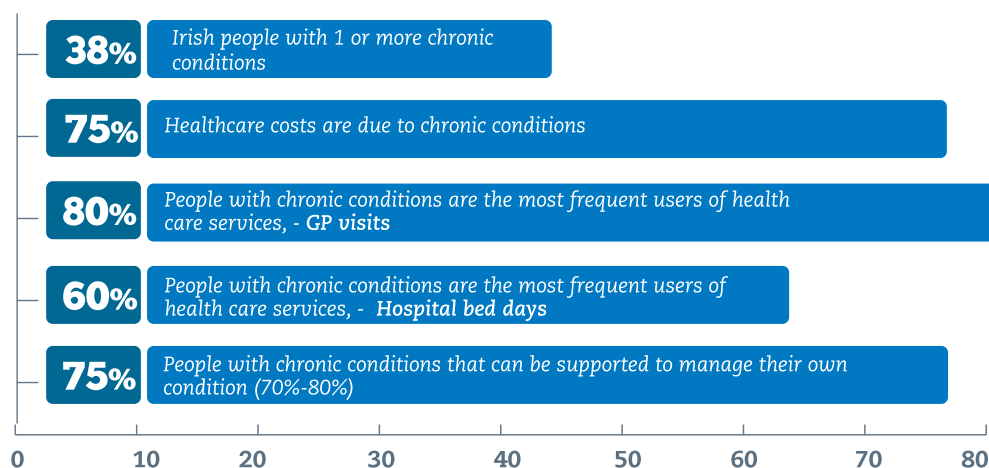
At Arthritis Ireland we recognise the pivotal role that empowering people to self-manage with a chronic condition, like arthritis, plays in enabling them to live well with their condition. Since no cure exists, learning to live well with arthritis is crucial to ensure people have a good quality of life. That is why we have pioneered the **Living Well with Arthritis self-management programme in Ireland**, rolling out courses nationwide for people with arthritis and other musculoskeletal disorders for the past 7 years.

During that time almost 3500 people have participated in nearly 200 courses across Ireland.

This report charts our journey with self-management since 2006 and firmly plants self-management at the forefront of the solution to addressing the rising tide of chronic conditions.

"The course has enabled me to look after myself more and that's why I rarely take time off sick from my job."
John, 52

Why is self-management important?



1 in 3 people have chronic conditions

"It taught me that I was in control of my disease, not the other way around."

Anne-Marie Gannon

“I had just had a new baby when I was diagnosed with arthritis. It was a very tough time for me. I was in an awful lot of pain and at the time the drugs used to treat it weren't great. I suffered a lot of joint damage and it got to the stage where I couldn't even pick my new son up. You lose your dignity because you lose the independence to do the most normal of things.

I couldn't drive, I found it very difficult even to have a shower or get dressed. I felt my life was over and on the really bad days I felt like I didn't want to live anymore. When I walked into the first day of the Living Well with Arthritis course, the overwhelming feeling I had was shock to see people who were actually younger than me there.

Before that I had never met anyone my own age who had arthritis. Everyone there felt the same and we all understood what the others had gone through. Learning self-management was the real turning point in my life with arthritis as it gave me the knowledge, support and confidence necessary to have a life.

It taught me that I was in control of my disease, not the other way around, and also how to communicate with my rheumatologist and doctor so that I get the best treatment. Most importantly it made me realise that I'm not alone and that there are lots of other people like me going through the same daily struggle.”

Age

52

Occupation

Retired (Bank Worker)

Type of Arthritis

Rheumatoid Arthritis,
diagnosed 18 years ago

Self-management: a vital part of the prescription

Self-management complements the clinical treatment and helps people learn to live happier, healthier lives.

Living with a condition for which there is no cure can have a devastating effect on a person. The impact can extend to social, economic, psychological, physical, cognitive and cultural aspects of a person's life. All of these factors can have a profound impact on a person's well-being and self-esteem. But people with chronic conditions can learn how to **manage their symptoms and adopt healthy behaviours**.

"I underestimated my own potential to cope with my condition. The course has made me feel confident and empowered me to take an active part in my treatment."
Siobhán, 38

Ultimately the key to the successful management of chronic conditions lies in the hands of the person who lives with the condition and their desire and ability to care about themselves. That is where self-management forms a vital part of the prescription.

Self-management involves the person with the chronic condition engaging in activities that protect and promote health, monitor and manage the symptoms and signs of illness, manage the impact of illness on functioning, emotions and interpersonal relationships and adhere to treatment regimes⁶. Simply put, self-management is what a person does to manage their condition.

The practice of self-management is especially important for those with a chronic condition such as arthritis, where only the patient can be responsible for his or her day-to-day care over the length of the illness.

For most of these people, self-management is a lifetime task. In the HSE's Chronic Illness Framework, the HSE states that it *"..will provide programmes to enable and enhance patients' self-management"*.

"Living with a chronic condition is very much like going on a walk in the woods. You're never quite certain what lies ahead of you".
Michael, 56

For over three decades now Professor Kate Lorig and her colleagues at the Stanford Patient Education Research Center in the US have been developing, evaluating, and translating into practice self-management programmes for people living with chronic health problems. All of the Stanford programmes are designed to help people gain self-confidence in their ability to control their symptoms, better manage their health problems, and lead fuller lives.

"Let me be clear - this is not support or group therapy. This is a scientifically structured education programme, designed on empirical evidence and has been proven to be an essential part of effective arthritis treatment that actually improves the performance of medication. We see people able to do things that they couldn't before, related to improvements in mobility and mood, and we see improvements in their quality of life".

Professor Kate Lorig, Director of the Stanford Patient Education Research Center and Professor of Medicine, Stanford University, US.





"It gave me a massive support network to tap into."

Peter Boyd

“I was 27 when I was diagnosed with fibromyalgia. An invisible illness of chronic pain, fatigue and stiffness, it was a difficult condition to come to terms with. Since then I have also been diagnosed with rheumatoid arthritis.

For a long time I felt trapped by my physical symptoms and beaten down by the emotional onslaught. It's been said that 'in space no one can hear you scream'. Well, confronted by fibromyalgia and rheumatoid arthritis, no matter how hard I screamed no one saw, understood or heard the pain, fatigue and exhaustion I was feeling.

My life now is very different from what I had mapped out for myself. I'm not able to work for now due to fibromyalgia and arthritis; I struggle each month to maintain payments on my home. From training nearly every single day, I no longer run and even a fast walk is sometimes too much for me.

This is where the support of the Living Well with Arthritis course stepped in to help me. This self-management course introduced me to others with the same problems and who were the same age as me. I was no longer so isolated and I had a massive support network to tap into.

I learned how to manage my pain and deal with the negative feelings that accompany arthritis and fibromyalgia. I have since gone on to become a self-management Leader so that I can pass on to others the skills that have helped me to manage my condition better.💡

Age

30

Occupation

Barman

Type of Arthritis

Fibromyalgia & Rheumatoid Arthritis, diagnosed 3 years ago and 6 months ago respectively

Self-management: transforming the lives of people with arthritis

Arthritis Ireland pioneered the Stanford University developed Arthritis Self-Management Programme – known as *Living Well with Arthritis in Ireland* – back in 2006.

This was in response to the needs of people with arthritis to help them deal with the complexities and life-transforming issues arising from living with arthritis.

Since that time, we have delivered almost 200 courses to nearly 3,500 people living with all types of arthritis and rheumatic diseases through a network of over 80 trained course Leaders and 2 Master Trainers, most of whom are themselves living with arthritis. The programme has been supported by an annual HSE grant and funds raised through the Arthritis Ireland branch network.

Research and evaluation are essential in providing the robust evidence that Arthritis Ireland's courses are effective and that funding is being well spent. To this end we carried out a review amongst course participants from 2006 to 2010 with very positive outcomes.

We utilised many of the evaluation tools laid out by Stanford University with questionnaires being completed by participants prior to starting the course, at the end of the course and at the 6 month and 12 month stages. The data was analysed by Arthritis Ireland and the University of Ottawa.



A 7% decrease in fatigue was recorded and sustained after 1 year. In relation to scores along the disability scale very positive results were shown with participants reporting 14% less disability around household chores and everyday tasks such as dressing and washing oneself. There was a 17% decrease, sustained at year 1, in participants' arthritis interfering with social activities.

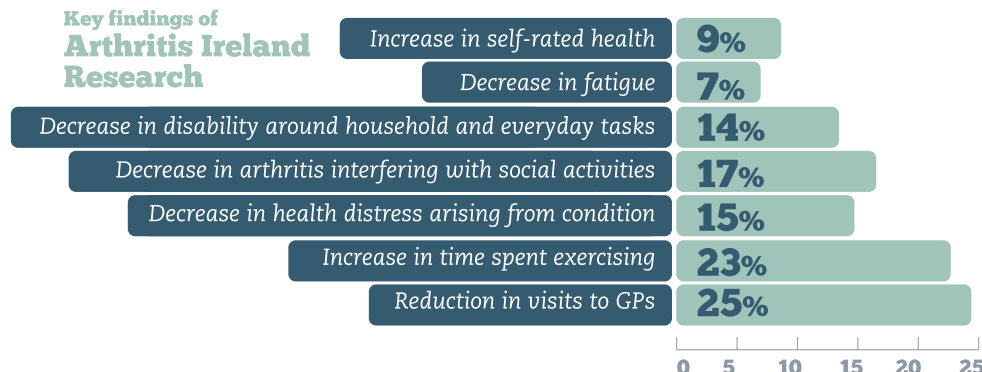
Encouragingly, given the strong medical evidence that exercise is safe and effective in the fight against arthritis, participants reported a significant uptake in exercise behaviour such as stretching and strengthening work and aerobic exercise was sustained even at the 1 year stage.

Some very encouraging results around the use of health care have shown that the *Living Well with Arthritis Programme* can reduce costs to the health system.

In our study, patients reported a 25% reduction in visits to GPs, fewer emergency department visits, fewer visits to the hospital clinic and fewer overnight hospital stays.

Furthermore, the programme has become a key tool for recruitment of highly engaged and committed volunteers for the organisation. The vast majority of volunteers involved in Arthritis Ireland support services are *Living Well with Arthritis* past participants, a noteworthy indicator of the powerful effect the course has had on their lives.

Key findings of Arthritis Ireland Research



In a 3 year evaluation of the Living Well with Arthritis Programme the results of the survey show that on completion participants have

- ✓ Improved their ability to cope with pain
- ✓ Become more active in managing their arthritis
- ✓ Increased their amount of regular exercise
- ✓ Improved their attitude towards living with their condition
- ✓ Increased their knowledge of their condition
- ✓ Reduced their visits to hospital and reliance on GPs



"I realised that dealing with my arthritis was up to me."

Maeve Halpin

“Initially it was very frightening when I was first diagnosed. I had visions of wheelchairs and the treatments weren’t great back then. It was all about steroids and gold injections. There was a lot of permanent joint damage done and there was a lot of pain in those early years. It had a very real effect on my life. I couldn’t open my hall door and I got stuck in various ladies toilets which wasn’t a nice experience. On various occasions I needed help coming down the stairs. The one thing that frightened me was that loss of independence.

The Living Well with Arthritis course helped me to address that. It gave me the courage to be in charge of my own arthritis; to say this isn’t my husband’s arthritis and it’s not my consultant’s arthritis.

They all play their part but it’s my arthritis and I have to be in charge of it. I realised that dealing with my arthritis was up to me, that I had to fight my corner and discipline myself. The way I would sum up the course is to say that it empowers you to take control. You accept that there will be both good times and bad times and in the bad times I allow myself a good moan and then say right it’s time to deal with this.

Now if I’m not happy with something in my treatment I say so; if I think I need to try something new, like a new exercise activity, I’ll do it. It’s a philosophy that I’m now very keen to pass on to others.”

Age

78

Occupation

Retired (Teacher)

Type of Arthritis

Rheumatoid Arthritis,
diagnosed 26 years ago

Self-management: it works!

Evidence suggests that supporting self-management works. Empowering people to look after themselves can improve their motivation, their symptoms and clinical outcomes and can even change how they use health services.

Evidence-based, self-management education programmes have been proven internationally to significantly help people with chronic conditions.

A major review carried out by the Centers for Disease Control (CDC) in the USA in 2008 and updated in May 2011, showed strong evidence that the Arthritis Self-Management Programme has a beneficial effect on physical & emotional outcomes and health-related quality of life.

The CDC studies found that the programme consistently results in greater energy/reduced fatigue, more exercise participation, fewer social role limitations, better psychological well-being, enhanced partnerships with physicians and greater self-efficacy. It is generally (although not always) associated with reductions in pain symptoms^{8,9}.

A 12 year review carried out by Lorig et al from 1987 to 1991 in the USA showed that patient education interventions can offer a further **15%-30% improvement in reported arthritis symptoms** on top of the improvements demonstrated by medical care, including the use of medications¹⁰.

Barlow et al published the first long-term evaluation of a community-based patient education intervention delivered in the UK in 1998. This research showed that after participation in the Arthritis Self-Management Programme, people with arthritis derive substantial and prolonged benefits in terms of perceived ability to manage arthritis, reduction in pain and improved psychological well-being¹¹.

Following the success of the Arthritis Self-Management Programme, Stanford University went on to develop the Chronic Disease Self-Management Programme, which is a generic programme for a broad range of chronic conditions. Research published in 2001 by Lorig et al reported on an evaluation where there were statistically significant improvements in seven of the nine health status measures: fatigue, shortness of breath, pain, social activity limitation, illness intrusiveness, depression and health distress.¹²

1987 - 1991

Lorig et al

Review shows that patient education interventions can offer a further **15%-30% improvement in reported arthritis symptoms** on top of the improvements demonstrated by medical care...

2001

Lorig et al

Reported significant improvements in health status measures; fatigue, shortness of breath, pain, social activity limitation, illness intrusiveness and depression...

2011

Centers for Disease Control (CDC)

Programme consistently results in greater energy/reduced fatigue, more exercise participation, fewer social role limitations, better psychological well-being...

1998

Barlow et al

Publishes the first long-term evaluation of a community-based patient education intervention delivered in the UK...

2010

Expert Patients Programme Community Interest Company (EPP CIC)

Publishes a report illustrating how economically beneficial targeted self-management could be for the NHS in the UK...

Currently...

Growing acknowledgment that, as a standalone intervention, self-management does provide benefits...



"The course reinforced in me the importance of a positive attitude and helped me to set goals and achieve them."

Claire Kinneavy

“Horrific is the only way to describe the first 10 years of my life with rheumatoid arthritis. I had to give up my job as a home economics teacher and even basic, domestic tasks had become very difficult. It was hard to keep going but I’d no option as I had 2 small children. Medications were not as good back then and I had permanent joint damage done as a result. I kept up a brave face but at the time I was feeling very scared by the prospect of surgery and felt terrible guilt because I felt I was a burden on my family.

When I read about the Living Well with Arthritis course in the Arthritis Ireland magazine I remember thinking I would travel to Timbuktu to do it. My expectation was that the course might be overly scientific in its messages but in reality it was simple, easy-to-understand information that helped me to manage my condition in a structured way.

The course reinforced in me the importance of a positive attitude and helped me to set goals and achieve them through action plans. It also gave me the confidence and motivation to seek out volunteering opportunities to fill the void I had been feeling since retiring from work.

That in turn got me more involved in community life which helped a lot with the feeling of isolation that so often accompanies rheumatoid arthritis. Last but not least, it enabled me to approach the everyday domestic chores with more confidence and equipped me with the communication skills to get the most out of my healthcare team. ☺☺

Age

55

Occupation

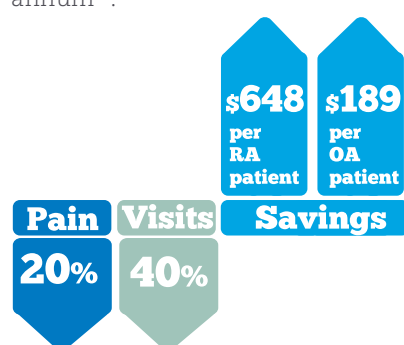
Retired (Home Economics Teacher)

Type of Arthritis

Rheumatoid Arthritis, diagnosed 31 years ago

Self-Management: it works! Continued...

A number of studies have provided strong evidence that Arthritis Self-Management Programmes not only pay for themselves but provide a return on investment for the health system. The earliest study reviewed was that conducted by Lorig et al and demonstrated that pain had declined by 20% and visits by 40% with estimated savings to the health system of \$648 per rheumatoid arthritis (RA) patient and \$189 per osteoarthritis (OA) patient per annum¹³.



Another more recent study by Lorig et al reported that at 1 year follow-up, participants in the Arthritis Self-Management Programme experienced statistically significant improvements in health status that resulted in fewer visits to the emergency department. There were also fewer outpatient visits to physicians and fewer days in hospital¹⁴.

“Enabling patients to be more independent, knowledgeable and ultimately healthier, and therefore less reliant on health service support is a key objective of self-management education tools. The National Clinical Programmes are each striving to integrate the self-management tools and philosophy into the clinical pathways and guidelines it develops.”

Dr. Áine Carroll, National Director for Clinical Strategy and Programmes, HSE

In terms of the Chronic Disease Self-Management Programme a randomised trial conducted in the US by Lorig et al showed that in addition to the improvements at 6 months in weekly minutes of exercise, they also had fewer hospitalisations, fewer emergency department visits and days spent in hospital.¹⁵

Research conducted in 2001 looked at the potential cost savings to the health system arising from the Chronic Disease Self-Management Programme.

Taking \$1,000 as an average cost per hospital day and \$100 for an average cost of an emergency department visit, the expected savings would be \$990 per Arthritis Self-Management Programme participant in the first year.

At an average cost of \$200 per course participant, this suggests that the programme more than pays for itself at a cost-to-savings ratio of 1:4¹².

In February 2010, the Expert Patients Programme Community Interest Company (EPP CIC) published a report that also illustrated how **economically beneficial targeted self-management could be for the NHS in the UK.**

It demonstrated a ratio of 3:1 – in other words, for every £1 invested, £3 was saved through improving participants’ quality of life and reducing avoidable hospital admissions¹⁶.

Recently, there has been growing acknowledgment that, as a standalone intervention, self-management does provide benefits, both personal and economic as outlined above. However, if it were to be integrated with HSE services and part of the patient care pathway then it is likely to produce greater cost savings though targeted referrals.

“People can learn in 6 weeks what it took me 20 years to discover. You can save yourself a whole lot of trial and error by doing one of their courses.”

Tim, 45



"It was great to be able to speak to others who knew exactly what it was like to have arthritis."

Erica Mitchell

“I was in the middle of a sports massage therapy course when I realised that my hands would become all stiff and claw-like. The stiffness and weakness spread around my body and got progressively worse. It got to the stage that I couldn't do basic everyday activities.

Even things like raising my hand to wash my hair or pulling the brakes on my bike became impossible and to get down the stairs I had to walk backwards. I was eventually diagnosed with rheumatoid arthritis (RA) and at that point I discovered Arthritis Ireland. Having registered with them, I was told about the Living Well with Arthritis course.

Initially I was worried that everyone on the course would be way older than me but it wasn't like that. We had a whole spectrum of ages, from 27 right up to 93! I had done a lot of reading around rheumatoid arthritis and treatments so some of the information I was aware of already but the key thing for me was the peer support and the social aspect of the course.

It was great to be able to speak to others who knew exactly what it was like to have RA. Even after the course we still all met up for dinner regularly and even today, 7 years later, I am still in contact with the others.”



Age

35

Occupation

Computer Programmer

Type of Arthritis

Rheumatoid Arthritis,
diagnosed 8 years ago

The future of self-management in Ireland: key recommendations

There is no doubt that self-management does work. What follows are key recommendations to strengthen the role of self-management so that it can help the growing numbers of people with chronic conditions become active participants in their care and ultimately live happier, healthier lives.

- 1. Recognise that self-management programmes are a core clinical priority and be embedded into National Clinical Programmes for all chronic diseases;**

 - Clinicians and healthcare professionals need to refer patients to self-management programmes as a matter of course. If health professionals were to target those with greater needs who have emotional and environmental barriers to behavioural change then even **greater benefits will be realised**.
 - Self-management programmes are a low-cost intervention but currently **funding in this area is very limited**. More funding needs to be made available so that the infrastructure can be properly developed, enabling more people to access programmes in communities around Ireland and to realise cost savings to the health system.
- 2. Provide education and training to clinicians and healthcare professionals so that they develop a comprehensive understanding of the self management ethos and can promote it amongst their patients;**

 - The attitudes and skills of healthcare providers can have a significant effect on the extent to which **people feel engaged and supported** so further training is needed for clinicians in the core competencies of self-management.
 - Within undergraduate and postgraduate 3rd level health professional education, formal training on self-management should be given to **ensure students have a comprehensive knowledge of the self-management programme** and an understanding of its philosophy.
- 3. Recognise the vital role of the voluntary sector as a key driver of success;**

 - Evidence clearly shows that **better outcomes for patients are achieved when self-management programmes are delivered** by lay people in a community setting. This model should be followed whenever possible.

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About the Arthritis Self-Management Programme

The first patient education programme that was developed in Stanford was the Arthritis Self-Management Programme. Indeed it is the prototype for all subsequent programmes developed in the Center.

It is this programme that Arthritis Ireland has adopted and since its introduction in 2006, has delivered the programme to over 3,500 people living with various types of rheumatic diseases, in nearly 200 courses provided by a network of over 80 trained Course Leaders.

The Arthritis Self-Management Programme (delivered as *Living Well with Arthritis* in Ireland) is an educational workshop for people with arthritis - including osteoarthritis, fibromyalgia, rheumatoid arthritis, lupus.

The programme:

- is designed to be taught in a community setting, such as a community center, parish hall, and library.
- is offered as a 2 ½ -hour per week workshop for 6 weeks.
- is led by trained leaders who have arthritis and/or another rheumatic disease themselves and some health professionals, who follow a structured leader protocol.
- helps participants learn how to take control of their chronic condition.
- encourages interaction and mutual problem-solving and support.
- is designed to complement clinical treatment and disease-specific education programmes

Subjects covered on the *Living Well with Arthritis* Self-Management Programme include:

1. techniques to deal with problems such as pain, fatigue, frustration and isolation,
2. appropriate exercise for maintaining and improving strength, flexibility, and endurance,
3. appropriate use of medications,
4. communicating effectively with family, friends, and health professionals,
5. healthy eating,
6. making informed treatment decisions,
7. disease-related problem-solving
8. getting a good night's sleep



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*The production of this report has
been made possible by a grant from*

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