



JointHealth™ Education

Psoriatic Arthritis and Ankylosing Spondylitis

ACE launches new JointHealth™ Education Psoriatic Arthritis and Ankylosing Spondylitis courses

In this issue of JointHealth™ insight, we introduce two new JointHealth™ Education (JHEd) courses: Psoriatic Arthritis (PsA) and Ankylosing Spondylitis (AS). We take an in-depth look at the courses and share new research findings in both disease areas, including psychosocial experiences of patients with PsA and new exercise recommendations for AS.

Arthritis Consumer Experts (ACE) has launched two new **JointHealth™ Education** courses: JHEd PsA and JHEd AS. Each disease specific course includes 6 lessons that are interactive and evidence-based. The courses are designed to empower PsA and AS patients by equipping them with the knowledge, skills and confidence to be equal partners on their healthcare team.

“JointHealth™ Education was inspired by many of ACE’s members living with an inflammatory arthritis who have told us they lack the knowledge and communications skills to have full, satisfying conversations with their rheumatologists. A patient’s perception of their inflammatory arthritis, such as PsA or AS and its treatment, as well as their relationship with their healthcare provider, impacts the management and the outcomes of their disease. Our graduates who have taken JointHealth™ Education courses have told us the program has improved their ability to communicate with their rheumatologists and helped achieve the best possible outcomes for their disease management.”

- Cheryl Koehn, Founder and President, Arthritis Consumer Experts

“Canadian rheumatologists have been actively discussing and pursuing ways to improve communication between patients and rheumatologists in order to work together to set treatment goals and establish a treatment plan to achieve the best possible disease outcomes. JointHealth™ Education is a great program not just for patients, but also for rheumatologists – junior and senior, alike. We need to see our patient’s experiences, needs and goals through their eyes and words.”

- Kam Shojania, MD, FRCPC, Clinical Professor and Head, Division of Rheumatology, University of British Columbia, and Medical Director of the Mary Pack Arthritis Program

Each course gives you the key facts or “speaking points” to cover during your appointments with your rheumatologist and in your life with family, friends and at work. The Lesson Plan starts with information and tips on fine tuning your communication and listening skills and ends with information on how to manage your world with PsA or AS in between your appointments. Each lesson includes easy to read content, a short quiz and a coaching video for your viewing. When all three lessons are completed, you will receive a “graduation certificate” by email.



The courses highlight different disease specific information based on the latest research and clinical recommendations. The psoriatic arthritis course is also based on findings from a recent [global study](#) on the experiences of people living with PsA. The content for each course has been reviewed by a board of scientific directors and rheumatologists to ensure clinical accuracy.

What is JointHealth™ Education?

The JointHealth™ Education program was launched in 2016 and now includes five user friendly, on-line, courses:

1. JHEd: Rheumatoid Arthritis (RA)
2. JHEd: Advanced therapies for Inflammatory Arthritis
3. JHEd: Biosimilars Education Video Series
4. JHEd: Psoriatic Arthritis (PsA) **NEW!**
5. JHEd: Ankylosing Spondylitis (AS) **NEW!**

Since 2016, JointHealth™ Education has graduated over a thousand arthritis patients and equipped them with the skills necessary to succeed as equal partners in their own care. If any of these courses are of interest to you, whether you are a patient yourself, care-taker, friend or family member of a patient, we encourage you to register: bit.ly/ACE-JHEd



What you'll learn



Lesson 1 – The Art of Communication with Your Rheumatologist

Topics include:

- Getting ready for your appointment with your rheumatologist
- Getting comfortable in your rheumatologist's office
- Communication warm-up
- The essentials for effective communication with your rheumatologist

Lesson 2 – Understanding your PsA or AS diagnosis

Topics include:

- The facts about PsA or AS
- Getting diagnosed
- Treatment basics
- The latest research on PsA or AS

Lesson 3 – Setting treatment goals and building a treatment plan

Topics include:

- Time management
- Asking questions, sharing fears and concerns, and listening
- Setting treatment goals
- Making a treatment plan

Lesson 4 – Talking about PsA or AS treatments

Topics include:

- Evidence-based treatments
- Making treatment choices with your rheumatologist
- Sticking with your treatments
- Monitoring the effectiveness of your treatments and treatment plan

Lesson 5 – Self-care and PsA or AS

Topics include:

- Taking charge of what you can control
- Elements of a self-care plan
- At-home self-care treatments
- Caring for your mental health
- Sharing your self-care success with your rheumatologist

Lesson 6 – Managing your world with PsA or AS

Topics include:

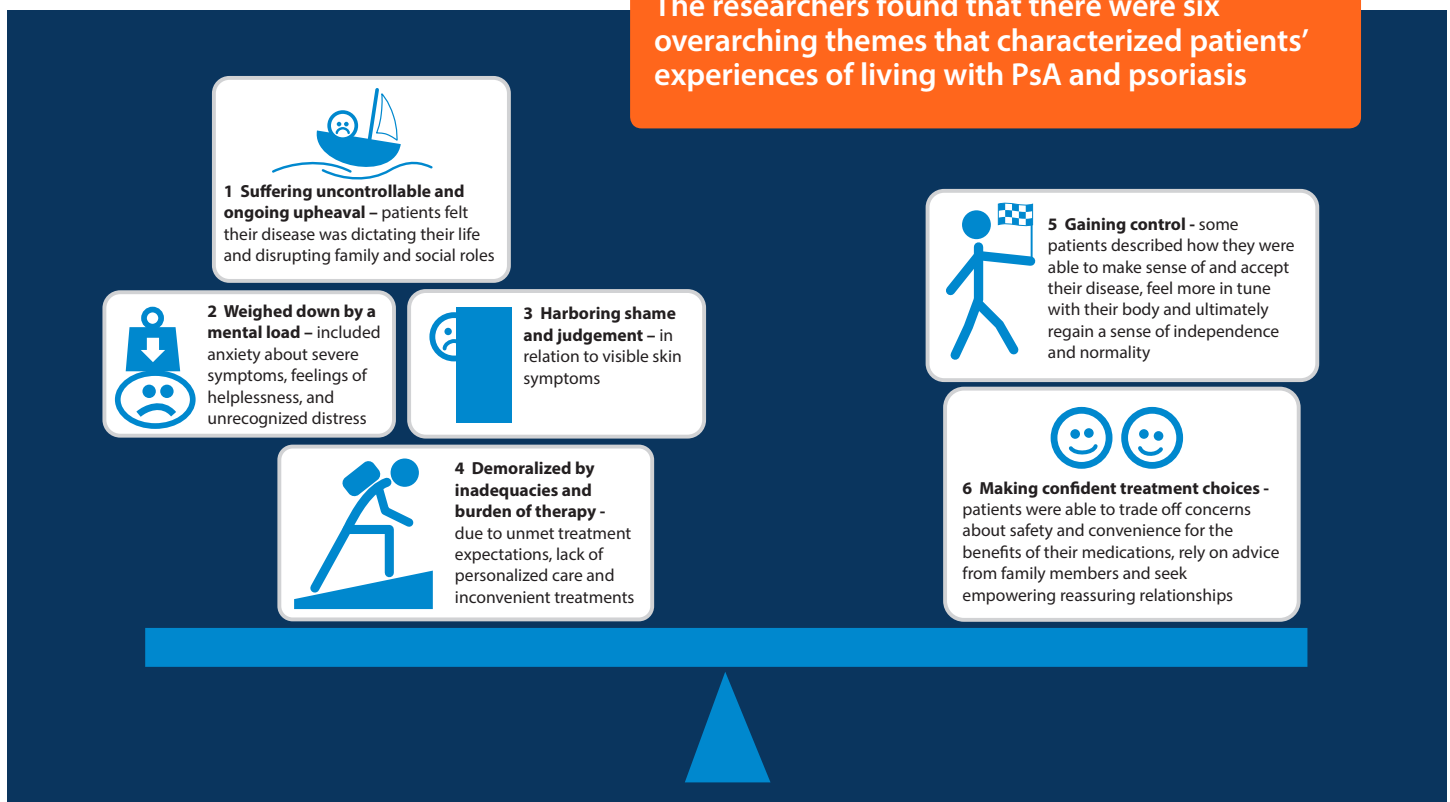
- How to explain PsA or AS to the people in your world
- PsA or AS and its effect on relationships
- Communication tips to help you in your disease journey
- Asking for support and help
- Your sexuality and PsA or AS
- Your disease at work

Psychosocial experiences and unmet treatment expectations of patients with PsA and psoriasis

In March 2019, Dr. Danial Sumpton, Rheumatologist, Concord Repatriation General Hospital, and his research team published a [study](#)¹ that aimed to identify gaps in patient care for PsA and psoriasis. The team conducted a systematic literature review, analyzing a large number of existing studies from around the world that looked at experiences of adult patients with PsA and psoriasis. The review allowed researchers to look at more data on patient

experience then could be collected with one individual study. Sumpton and his team analysed 56 studies that represented 1,147 patients with psoriasis and 337 patients with PsA. These studies collected information about patient experiences through individual interviews as well as focus groups where several patients shared their experiences together in the same room.

The researchers found that there were six overarching themes that characterized patients' experiences of living with PsA and psoriasis



These findings are both concerning and encouraging. While they point to significant gaps in care for psychosocial symptoms of PsA and psoriasis, uncovering these gaps is the first step towards addressing them. In addition, the study shows that there are also ways to feel empowered and in control of one's disease. Sumpton added: "*[patients] felt empowered when they developed an understanding of the pathophysiology [i.e. disease] and link between psoriasis and arthritis and gained a broader insight into treatment options to advocate for their use.*" Arthritis Consumer Experts' online education course can help patients do exactly this. JHEd PsA helps patients build disease knowledge and communication

skills so that they can be equal partners on their healthcare team. This ensures that the patients' values and goals are accounted for and that they feel confident about their treatment plan rather than feeling disempowered by unmet treatment expectations. The course also provides tips on how to care for your mental health, feel in control of your disease, and manage social and intimate relationships. To learn more about the complex relationship between mental health and arthritis, read our [February 2019 issue of JointHealth™ insight](#).

1 Sumpton D, et al. "Patients' perspectives and experience of psoriasis and psoriatic arthritis: a systematic review and thematic synthesis of qualitative studies". Arthritis Care and Research. March 2019 <https://doi.org/10.1002/acr.23896>

Exercise recommendations in ankylosing spondylitis

There is an international consensus that exercise is beneficial in ankylosing spondylitis (AS), but there is little information to guide the type and amount of exercise needed for most benefit. Recently, a team of Australian researchers released 10 evidence-based and consensus-based exercise recommendations, which were published in *Science Direct* and featured in *RheumNow*.² "This collaborative project, combining evidence with clinical expertise, was established to develop practical recommendations to guide sustainable exercise prescription for individuals with AS," said lead author Janet Milner, Physiotherapist, Menzies Institute for Medical Research, University of Tasmania.

- 1. Assessment** - A patient's exercise prescription should be based on a thorough clinical assessment measuring musculoskeletal and psychosocial factors, objective axial mobility (i.e. spinal mobility) and chest expansion.
- 2. Monitoring** - Patients should be provided with individual monitoring and feedback to help inform changing needs, make sure they understand the exercises and feel confident doing them. This monitoring should be done at least once a year, but could be more depending on symptoms, function and mobility.
- 3. Safety** - Clinicians should consider physical changes from AS when prescribing exercise, especially for those with more severe AS or a later onset of the disease.
- 4. Disease management** - AS patients who are taking anti-TNF medications (biologic medications) should continue with exercise prescription because it gives an additional benefit to the medications alone.
- 5. AS-specific exercise** to help with mobility - For the best management of AS, exercise prescription should focus on spinal mobility. Maintaining the mobility of peripheral joints (e.g. knees, shoulders, hands, feet, hips) is also very important.
- 6. Other AS-specific exercise** - Stretching, strengthening, cardiopulmonary and functional fitness are important parts of a balanced exercise program. Functional fitness are exercises that prepare the body for real-life activities and daily tasks. Cardiopulmonary fitness, or aerobic fitness, helps strengthen the heart, lungs and muscles.
- 7. Physical activity** - Regular physical activity should be encouraged; it promotes general health, well-being and functional outcomes. Physical activity includes things you already do in your everyday life, such as walking to work or transit, walking up and down stairs, gardening, and playing with children.
- 8. Dosage** - Specific aspects of an exercise program such as frequency, intensity, duration and type should be customized according to the patient's clinical assessment, personal goals, and lifestyle.
- 9. Adherence** (sticking with an exercise program) - Healthcare providers should encourage motivation, promote on-going self-management, and assess how patients are maintaining and continuing their exercise program.
- 10. Exercise setting** - For the best outcomes, priority should be given to patient preference in exercise choice. For example, does the patient prefer exercising with a group, indoors or outdoors, or alone at home?



Are you a JointHealth™ Education graduate?

Have you completed one of ACE's JointHealth™ Education courses? How has it helped you discuss what is most important for you in terms of treatment success? Are you more comfortable raising concerns/fear with your rheumatologist and asking questions during your clinical visit?

Your responses will help us improve our program and ensure it delivers what patients want.

Please email your comments to feedback@jointhealth.org

2 Milner J, et al. "Exercise for ankylosing spondylitis: An evidence-based consensus statement" *Science Direct*. February 2016. <https://doi.org/10.1016/j.semarthrit.2015.08.003>

Arthritis Consumer Experts (ACE)

Who we are

Arthritis Consumer Experts (ACE) operates as a non-profit and provides free research based education and information to Canadians with arthritis. We help (em)power people living with all forms of arthritis to take control of their disease and to take action in healthcare and research decision making. ACE activities are guided by its members and led by people with arthritis, scientific and medical experts on the ACE Advisory Board. To learn more about ACE, visit www.jointhehealth.org

Guiding Principles

Healthcare is a human right. Those in healthcare, especially those who stand to gain from the ill health of others, have a moral responsibility to examine what they do, its long-term consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and for-profit organizations. This is not only equitable, but is the best means to balance the influence of any specific constituency and a practical necessity. Any amount remaining from our annual budget at year end remains with ACE and is used to support the following year's core programs to continue helping Canadians living with arthritis.

For its past 20 years, ACE has consistently honored a commitment to its members and subscribers, academic and healthcare professional

colleagues, collaborators, government and the public that its work is free from the influence of its funders.

To inform ACE employees and our stakeholders, members, subscribers that we will operate our organization with integrity and abide by the highest standards of lawful and ethical behaviour, ACE has adopted this strict set of guiding principles:

- ACE requests grants from private and public organizations to support its core program and plans and allocates those funds free from influence;
- ACE discloses all funding sources in all its activities;
- ACE does not promote any "brand", product or program on any of its materials or its website, or during any of its educational programs or activities.
- ACE employees do not receive equity interest or personal "in-kind" support of any kind from any health-related organization;
- ACE identifies the source of all materials or documents used;
- ACE develops positions on health policy, products or services in collaboration with people living with arthritis, academic research community, health care providers and governments free from concern or constraint of its funders or other organizations; ACE employees do not engage in personal activities with its funders;
- Cheryl Koehn does not own stock or any financial interest in any of its private or public funders.

Scientific Review

ACE thanks Arthritis Research Canada (ARC) for its scientific review of all ACE and JointHealth™ materials.



Disclosures

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ACE also received unsolicited donations from its community members (people with arthritis) across Canada.

ACE thanks funders for their support to help the nearly 6 million Canadians living with osteoarthritis, rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis and the many other forms of the disease.

Disclaimer

The material contained in this publication should not be relied on to suggest a course of treatment for a particular individual or as a substitute for consultation with qualified health professionals who are familiar with your individual medical needs. Please contact your physician for your own health care related questions.

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ACE does not promote any "brand", product or program on any of its materials or its website, or during any of its educational programs or activities.

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