

Education

Arthritis and family: the importance of healthy communication

An arthritis diagnosis can affect every area of your life, including your family. It is critically important, and often very difficult, to create and maintain open communication with your family about your disease. Not being open about feelings, needs, worries, and fears can lead to isolation, resentment, and depression for people living with arthritis and for their families.

In this issue:

Education

- Arthritis and family: the importance of healthy communication
- Advice for partners of people living with arthritis
- Intimacy and arthritis

Listening to you

- Update your email or postal address

Arthritis Consumer Experts (ACE)

- Who we are
- Guiding principles and acknowledgement
- Disclaimer

JointHealth Monthly is available in print and online in English and français.



Arthritis Consumer Experts™

910B Richards Street, Vancouver BC V6B 3C1
t: 604.974.1366 f: 604.974.1377
tf: 1.866.974.1366

**e: info@arthritisconsumerexperts.org
www.arthritisconsumerexperts.org**

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

© ACE Planning & Consulting Inc. 2007

Communicating with partners

The research community has recently begun to examine in detail the powerful effects that arthritis can have on relationships. Recent studies are confirming what many people with arthritis have long known from personal experience. A diagnosis of arthritis can have a tremendous impact on all areas of a person's life, and this certainly includes relationships with partners.

Recent studies have also shown that people with arthritis who are in strong relationships tend to have lower levels of physical disability. We know, therefore, that working on your relationship as a whole, by improving your communication and strengthening your systems for supporting one another, can actually improve your health.

"One of the most important things to learn when you are living with a chronic illness is how to ask for support or help."

One of the most important things to learn when you are living with a chronic illness is how to ask for support or help. Support can take many forms, including physical assistance, emotional support, or information and advice. Many people have difficulty asking for support or help, especially if they are used to being very self-sufficient. Practice asking your partner

for things you need, and ask your partner to practice responding in a way that does not make you feel guilty for having to ask.

Work on maintaining open communication with your partner about how you are feeling physically. Allen Lehman, a PhD Candidate at the University of British Columbia, recently found in his research on more than 200 couples affected by RA that about one-third to one-half of spouses overestimate or underestimate the severity of fatigue or pain the person with RA experiences. People living with arthritis whose spouses underestimated their fatigue levels were more likely to report poorer social support from their partners.

It is important to ask your partner what he or she is finding challenging about supporting you with your arthritis, and make clear statements about what types of support are helpful to you, and which are not helpful. If possible, try to have these discussions when you are feeling calm and loving towards your partner, and not when you are tense or frustrated. You will probably find that speaking openly and honestly is much easier when you are not upset or angry.

Maintaining good, healthy communication is key to keeping your relationship healthy and functioning. Studies indicate that the state of the pre-arthritis relationship has a profound impact on the post-arthritis relationship. Simply put, stronger relationships fare better than weaker ones when arthritis is introduced into the mix. It makes sense, then, to work to make all of the areas of your relationship the best they can be.

Communicating with children

For many parents, the most difficult thing about learning to live with arthritis can be adjusting

continued on page 2

Education

Arthritis and family ... continued

your expectations of yourself as a parent. It can be tremendously difficult to accept that there are some things that you will no longer be able to do in the same ways. You may feel reluctant to speak openly with your children about your disease for fear of frightening them.

Maintaining an open, honest relationship with children is vital when you are living with a chronic

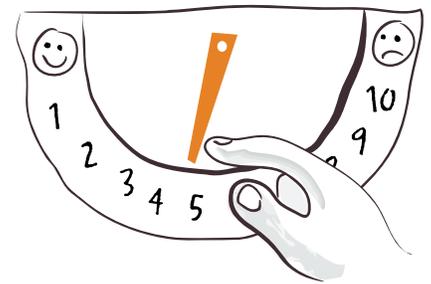
"Children need to know what to expect, ..."

disease. Children need to know what to expect, and need to feel that it is safe to discuss feelings and anxieties they may be having about your health.

Many people have found it helpful to come up with a system for keeping your family aware of how you are feeling. Because many people with arthritis experience symptoms which are invisible, like pain and fatigue, families, including children, can have a hard time knowing how you are feeling.

Here are two examples of strategies for communicating with your children:

- Establish a number scale, from 1 (none) to 10 (extreme), to rate your pain and fatigue. If your children know that you are a 2 today, they'll know that they can expect a more cheerful, energetic parent; if you are an 8 or 9, they will know to ask for less, and you won't feel guilty for saying "no".
- If your children are young, consider making a



Make something like this from a paper plate and fix it on the fridge

chart with happy and sad faces. On days when your symptoms are worse, display the sad face; when you are feeling better, display the happy face. Children can look at the chart through the day and be reminded of your pain and fatigue levels. ◀

Education

Intimacy and Arthritis

Recently, several studies have examined the impact that arthritis can have on intimacy and sexuality within relationships. One recent study, conducted by Dr Gillian Grundy, found that joint pain, fatigue, fear, and reduced physical function profoundly affected sexual function, frequency of intercourse, and sexual satisfaction.

For many couples, intimacy and sexuality are profoundly important. Arthritis can certainly present challenges in these areas, but there are many ways to lessen its impacts and continue to enjoy a healthy, active sexual life.

Timing

Depending upon which type of arthritis you have, timing is very important when planning for intimacy.

For people with inflammatory arthritis, early morning may be the time of day when symptoms, including joint stiffness, are at their worst; it may make sense, therefore, to plan intimacy for later in the day.

People with osteoarthritis, on the other hand, may find that joint pain is worst towards the end of the day; in that case, intimacy might be most comfortable in the morning hours.

Preparation

As with any physical activity, there are some simple steps you can take while preparing to be intimate that may help prevent or minimize discomfort.

- Try taking a hot shower or bath before lovemaking to relax joints and muscles
- Take your pain medication 30 minutes before you plan to be intimate; that way, they will start to work right when you need them
- Ask your partner for a gentle massage
- Stretch out, as you would when preparing for any type of physical activity.

Positions

Choose positions which put the least amount of strain on your affected joints. Place pillows under knees, hips, and any other joints you are worried may be strained. There are several books that provide helpful tips about positions to protect specific joints, including *"Rheumatoid Arthritis: Plan to Win"* by Cheryl Koehn.

Planning

For many couples, accepting that intimacy will need to be more planned and less spontaneous is one of the first steps towards adapting to life

with arthritis. Because timing and preparation may help to make intimacy more enjoyable when you are dealing with arthritis, you may need to change how you think about intimacy.

Discuss your need for planning, timing, and preparation openly and clearly with your spouse. You will probably find that, when presented with simple, enjoyable ways to plan and prepare for intimacy, your spouse will be more than willing to accommodate your needs. ◀

"For many couples, intimacy and sexuality are profoundly important."

Advice for partners of people living with arthritis

Partners of people with arthritis face many unexpected challenges. Very often, an arthritis diagnosis comes as a shock, leaving both the diagnosed person and their spouse unprepared and unsure of how best to move forward.

Spouses of people living with chronic disease are often forced to adjust expectations, roles, and responsibilities within a very short period of time. It is important to realize that chronic disease affects both people in a partnership, and partners need to take responsibility for their own well-being; after all, you can be of very little help to your partner during his or her illness if you're not able to take good care of yourself.

Here are some things to consider when your partner is living with arthritis:

Take good care of yourself

Make a list of things you love to do, or things that you have always wanted to do or try. These could be simple, small indulgences, like getting a massage, going for a weekly swim, or taking enough uninterrupted time alone each day to read the newspaper. It could also be something more complicated, like traveling alone through Mexico, or learning to ride a motorcycle.



Once you've made your list, choose one or two that you think may fit into your life at the present time. Whatever you choose, make a commitment to yourself to make it happen. You will be a

better support person and care-giver if you are happy, relaxed, and fulfilled.

Accept your feelings

Know that you are not superhuman; do not expect yourself to be perfect, and do not punish yourself for feeling angry, resentful, or

"you can be of very little help ... if you're not able to take good care of yourself."

disappointed about the impact of arthritis on your relationship.

Accept that your feelings are normal and understandable. You have experienced a tremendous change, and the roles in your relationship may be shifting quickly and radically.

It is important to discuss your feelings. Your partner is probably the ideal person to talk to, but if that is not possible, or if you feel uncomfortable, consider speaking with a close friend, family member, or trained therapist.

Whoever you choose to speak to, remember that it is very important to share your feelings honestly. Keeping difficult feelings to yourself could result in becoming withdrawn and depressed. You need to be as healthy and happy as possible when you are facing the challenges a chronic disease presents to a relationship.

The right kind of support

Ask your spouse which types of support are helpful, and also which types are not. Research has shown that what one spouse imagines to be helpful, the other spouse may not. When a partner who thinks they are being supportive is not seen as supportive, notes Allen Lehman, it is more likely that the person living with arthritis will report poorer well-being. Listen to your partner, and try to give the support requested.

For example, your partner may want you to always do the tasks around the house which involve heavy lifting, like taking out the garbage,

lifting loads of laundry, or bringing in groceries. You may have been thinking that it was enough to be available to respond to individual requests, not understanding that having to ask continually may make your partner feel like a "nag".

Once you have had an open, honest discussion about helpful types of support, you will be able to understand how best to help.

Acknowledge your losses, and your gains

You may feel as if your spouse's arthritis diagnosis has changed everything, and that might be true. Old roles—breadwinner, sexual partner, co-parent—might not be as easily defined, and your spouse may be less able to play an active part in many areas of your family life.

It is important to acknowledge to yourself what you have lost. You may find it helpful to speak with someone, like a close friend or a counselor, about what you are feeling.

Remember that, while you have probably suffered losses, you may also be able to find that some good has come from your partner's disease. You may have experienced deeper communication, a strengthening of your commitment, a heightened awareness of good times. It is as important to acknowledge and discuss these positive developments as it is to be honest about your losses. In fact, recent research reveals that people with arthritis who believe something good has come from their experience with disease report less physical disability over time. <

Listening to you

We hope you find this information of use. Please tell us what you think by writing to us or emailing us at info@arthritisconsumerexperts.org.

Through your ongoing and active participation, ACE can make its work more relevant to all Canadians living with arthritis.

Update your email or postal address

Please let us know of any changes by contacting ACE at info@arthritisconsumerexperts.org.

This will ensure that you continue to receive your free email or print copy of JointHealth™ monthly.

Arthritis Consumer Experts

Who we are

Arthritis Consumer Experts (ACE) provides research-based education, advocacy training, advocacy leadership and information to Canadians with arthritis. We help empower people living with all forms of arthritis to take control of their disease and to take action in health care and research decision making. ACE activities are guided by its members and led by people with arthritis, leading medical professionals and the ACE Advisory Board. To learn more about ACE, visit

www.arthritisconsumerexperts.org

Guiding principles and acknowledgement

Guiding Principles

Health care is a human right. Those in health care, 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 profit from our activities is re-invested in our core programs for Canadians with arthritis.

To completely insulate the agenda, the activities and the judgments of our organization from those of organizations supporting our work, we put forth our abiding principles:

- ACE only requests unrestricted grants from private and public organizations to support its core program.
- ACE employees do not receive equity interest or personal "in-kind" support of any kind from any health-related organization.
- ACE discloses all funding sources in all its activities.
- ACE identifies the source of all materials or documents used.
- ACE develops positions on health policy, products or services in collaboration with arthritis consumers, the academic community and health care providers and government free from concern or constraint of other organizations.
- ACE employees do not engage in any personal social activities with supporters.
- ACE does not promote any "brand", product or program on any of its materials or its web site, or during any of its educational programs or activities.

Thanks

ACE thanks the Arthritis Research Centre of Canada (ARC) for its scientific review of JointHealth™.



Acknowledgement

Over the past 12 months, ACE received unrestricted grants-in-aid from: Abbott Laboratories Ltd., Amgen Canada / Wyeth Pharmaceuticals, Arthritis Research Centre of Canada, AstraZeneca Canada Inc., Bristol-Myers Squibb Canada, GlaxoSmithKline, Hoffman-La Roche Canada Ltd., Merck Frosst Canada, Pfizer Canada and Schering Canada.

ACE thanks these private and public organizations.

Disclaimer

The material contained in this newsletter is provided for general information only. It 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. Should you have any health care related questions or concerns, you should contact your physician. You should never disregard medical advice or delay in seeking it because of something you have read in this or any newsletter. <


Arthritis Consumer Experts™
910B Richards Street, Vancouver BC V6B 3C1

