PSC PARTNERS
SEEKING A CURE

Guidance for Caregivers - Points to Consider (April 2015)*
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I. General

- Caregiving is unique to the person - one size does not fit all. A caregiver for a child with PSC (PSCer) is likely to be much more involved than the parent for an adult person with PSC.
- Some people with PSC may not want to discuss/acknowledge they have the disease and may rely on their caregiver to keep the PSCer informed; other PSCers may want to assume full control, with their caregivers serving more of an ancillary role (e.g., record keeping).
- Remember others in the family. As a caregiver, don't let yourself be consumed by the disease to the extent these relations may be adversely impacted.
- As a caregiver, one of the best skills is not control, but rather the ability to help effectively manage situations that arise. This may involve identifying the problem/issue, listing strategies to address this (including possible resources), evaluating the results, and, if appropriate, substituting or suggesting another idea or strategy. It also is worth remembering that not all problems are fully solvable, and that the discussion itself can have a beneficial aspect.
- As a caregiver, you cannot do everything and still maintain your own health. Identify what needs to be done and identify the appropriate person/area that may be able to assist, and then effectively communicate that need. Remember that many times there are people (other family members, friends, and community resources) interested in helping, and who are willing to do so if asked.
- As a caregiver, you are faced with many challenges. While it is normal to have feelings of fear, anger, and uncertainty, it also is important to get beyond these negative feelings. Keeping a positive, realistic outlook can help you to develop strategies for handling a given situation, rather than get caught in extended feelings of helplessness.

II. The PSCer - Caregiver Relationship

- A person with PSC is first and foremost a person, and should not be defined by his or her disease. Maintain a normalcy of daily life to the fullest extent possible. You may want to be careful of regularly asking questions such as "How do you feel today?", "What is your pain level on a scale of one to ten" as these may tend to narrow the scope of the interactions and of the person's identity.
- Be careful with words or expressions like "We understand" or "I know how you feel." Remember, <u>we don't</u>. What is important is to be a good listener. Sometimes it is good to reflect back to the person what you hear being said; for example, "I hear you saying you are in a lot of pain today, how can I help?" This type of comment creates a more supportive environment, one that lets the person know that he or she is being heard.
- Some stress/conflict is to be expected in the relationship between the caregiver and the person with PSC. Good communication skills can help lessen this occurrence. One positive strategy can be the use of "I" instead of "You." "You" messages (such as "You said", "You need") may lead to defensiveness, anger, frustration, etc. "I" messages (such as "I would like to see if we can work out a plan", or "I need your help") allow for a more cooperative, problem-solving, less contentious approach. In dealing with interaction concerns, it is helpful to look for common ground and to try and develop a strategy or approach that best meets the needs of the involved persons. Ordinarily it is

best to avoid providing unsolicited advice, or, if such advice is provided, to do so in the form of asking, e.g., "have you thought about" or "do you feel it would be helpful to".

- Whatever role the caregiver assumes, it is very important to continue to maintain your primary roles: parent of a child with PSC, a spouse, a sibling, and not let the disease eat away at that relationship.
- One objective is to be a team, the PSCer and caregiver(s), with the involved people defining the operation of that team.

III. Make Time for Yourself

- Don't forget yourself! This is a critical component to make time for self. The PSCer may feel bad about how their disease has impacted your life. By taking care of yourself, through a hobby, vocation, days away, etc., you are not only recharging yourself and helping to avoid a "burnout", but you also may be lessening possible "guilt" feelings held by the PSCer.
- Don't overdo or dwell on the disease(s). It is understandable to periodically allow yourself a few seconds to feel awful about how bad things are, but then refocus on the more positive aspects. Keep in mind, and try to follow and share with your PSCer, the belief that yes the disease exists, but it is not going to control our existence.
- Make use of support groups: including friends, the PSC website, community and/or religious organizations. These entities can provide information, suggestions, and a constructive method of releasing your concerns/tensions.
- As in any stressful situation, there are a number of constructive outlets that may work for you: keeping a journal, exercising, talking with friends. Some other stress reducers are the use of humor, soft music, reading, knitting, other activities you enjoy, and accomplishment of a task.

IV. PSC and Caregivers

- Educate yourself by learning about the disease. Read information on the PSC Partners Seeking a Cure website, from reliable medical facilities and from other credible sources.
- Become familiar with the disease symptoms such as fatigue, itching, and jaundice.
- Become familiar with medical terms and procedures, such as ERCP, MRCP and blood test results.
- Become familiar with the medications and their possible side effects.
- The object is not to be an expert, but rather to maintain an awareness. One suggested resource is the PSC Partners Facebook Group. This resource provides advice for you to consider, and can provide both practical knowledge and an awareness that there are others who "get" what you are facing.
- This information is important on many levels: to help gauge the seriousness of any specific experience being faced by the PSCer, to better assess and understand actions and comments of medical practitioners, to educate both yourself and others and to be a stronger, more informed advocate.
- Learn what you need to be an educated, supportive caregiver and to deal with issues without being overly consumed. Everyone is different, but it is easy to spend too much time surfing the web and getting yourself upset finding every negative fact and figure that has been published.

V. PSC and Physicians

- Be respectful, but also remember that many doctors are not familiar with PSC.

- Try to choose a doctor that the PSCer and you are comfortable with, a doctor who is able to listen as well as provide advice, a doctor who is willing to understandably answer questions.
- Getting a second opinion can be helpful. A second opinion means wanting more information and/or confirmation, it does not need to mean dissatisfaction with the primary doctor. Also, competent doctors are unlikely to feel threatened, but instead appreciate the additional review and discussion of findings. Peace of mind is also an important factor to consider.
- Be willing to consider/to explore/to make a change in doctors if you do not feel that the doctor is understandably answering your questions, or if the doctor gives indication that he or she is not sufficiently familiar with PSC and is not taking steps to become more knowledgeable about PSC.
- Remember that improved lab results do not necessarily mean the person is “getting better.” Be wary of a doctor’s knowledge if he or she relies on these tests to show how the PSCer’s condition is improving.

VI. Be an Advocate

- Become an advocate, but don’t forget your PSCer. To the extent feasible or desired by the PSCer, he or she should be the person making the decision or agreeing to a proposed course of action (more applicable to adult PSCers).
- Keep a contact list of persons: names, addresses, telephone numbers, topic area – and maintain records, dates, times, who was seen, what was said, etc. This list may include doctors and other medical staff, government entities, employers, pharmacies, insurance companies, and others.
- Related to this is to ask for and to get copies of everything (e.g., lab results, doctor reports). These can then be placed in a compartmentalized binder. Doing this provides at least three distinct advantages. The first is that the binder provides an organized medical history for a disease that can extend over many years. The second is that the binder can be taken to appointments. That way if a doctor does not have some information, the PSCer or you can pull out your copy for the Doctor to review. The third advantage is that the records obtained can be reviewed by the PSCer or you for accuracy (e.g., in regards to diagnosis, treatment, medications, and allergies).
- Ask hospitals and clinics about whether they provide access to portable electronic health records through a patient portal or some other electronic medium, and if they do, get information on how this can be accessed.
- Where needed, and agreed to by the PSCer, complete an authorization to speak on behalf of the PSCer with various entities: health insurance carriers, physicians, and credit card companies.
- You may want to keep a log or record of concerns and difficulties experienced by the PSCer between appointments. At the time of future appointments, this information can be provided to the PSCer (and/or referred to by you) for possible discussion with the medical practitioners. Relying on memory, over a period of time, loses its benefit.
- You may want to maintain medical information on the PSCer that may be helpful to medical professionals in their contacts with the PSCer. Examples of such information include: a list of all medications, including vitamins and supplements; identification of any allergies the person may have; past surgical interventions; full medical history; baseline mental status; advanced directives; substance abuse issues (both past and present); and diet. One approach that may be helpful is to place frequently needed and relevant information (e.g., medications, allergies, medical diagnosis) on 2x4 mailing labels, or on small laminated cards that the person can carry with them and provide to medical personnel in case of emergency, or when filling out medical forms.

- If you help the PSCer with his or her medications, establish an approach that allows you to be aware of when medications need to be refilled (either at the pharmacy or through a new prescription). To assist in this process, especially where multiple medications are taken, consider preparing medication dosages in one or two week pillbox sets.
- If agreeable to the PSCer, attend appointments, but remember the focus is on the PSCer, not on you. If you attend the appointments, take notes.
- With permission of the PSCer, read the various reports and try to get clarification where needed.
- With the agreement of the PSCer, ask questions in medical meetings. Where you believe it is needed, double-check the answers received with reliable sources of information.
- Where multiple doctors are involved, "insist" on having one doctor who serves as a medical coordinator. Because PSC may impact people differently, and because the PSCer often may have other diseases, the treatment process may involve the PSCer being seen by various doctors, often of different specialties. Some of these doctors may not be familiar with PSC, and their reports may contain inaccurate statements based on this lack of knowledge. This can have various negative impacts - including on the PSCer's state of mind; plus, if it is necessary to apply for disability, on the disability review process. A medical coordinator can pull the material together.
- For the most serious cases, it may be necessary to apply for social security and/or state disability benefits. Social security has specific procedures on its website for its program; it is suspected that states also have procedures, but these may not be set out in as much detail. At some point, you may want to become familiar with this type of information. In the event it does become necessary to apply for disability benefits, the documentation, and ensuring the accuracy of that documentation, will be very important. As a general comment, social security has separate definitions of disability for adults and for children.
- A word on hospital emergency rooms. These can be very unpleasant experiences for patients with PSC, as doctors may not be familiar with the disease. In such situations, it is important for the advocate to do all he or she can to educate staff, thus minimizing unnecessary problems. PSCers are known to say that they have been treated often enough to know their bodies and medications, such as the type of needle to use to effectively draw blood or medications to which the person is allergic. Caregivers should be attentive to ensuring that the emergency room medical staff is hearing, and responsive to, this information.
- Your communication skills are very important both in communicating with medical personnel (e.g., by letting them know that you are knowledgeable, by asking questions, and by providing concise information) and in educating others.

VII. Planning

- You might consider developing and maintaining an "important information" folder. Some possible items for this folder include information on PSC and any other disease(s) the person has, the names and contact information for treating medical personnel, and the relevant insurance information. When traveling, you may want to consider getting travel insurance that covers your trip. Prior to purchasing such insurance, it is suggested that you review the policy's definition for such terms as "stable" and "effective date" to make sure the policy covers your specific travel. If purchased, take the company's telephone number with you on your trip.
- Consider what might occur in the future for the person with PSC, and what might be needed from you, should certain conditions warrant it. Legal issues are one example. Some legal documents that persons with PSC should consider include preparing a power of attorney that sets out when someone

may act as legal representative, and make decisions on behalf of the PSCer; an advanced medical directive that lets the family and medical team know what medical treatments the PSCer wants and those that are not wanted; a statement on whether the PSCer wishes to be an organ donor; and a will that outlines what the PSCer wants done with his or her property in the event of death.

- You might consider developing and maintaining an inventory of your needs in the event of an emergency; for example, who will watch the house, pet care, and financial assistance.
- You might want to prepare a care package to take on trips. Some possible items may include food items that the person ordinarily is able to eat without excess problems, vomit bags, pertinent medical information, as well as the names and telephone numbers of persons to contact in case of need.
- You might want to prepare an emergency bag for use in the event the person needs to go to the emergency room. Some possible items may include snacks, comfort items, a toothbrush, a change of clothing, pertinent medical information, a small amount of money (e.g., for vending machines, other items), and the names and telephone numbers of persons to contact in case of need. You may want to develop a phone tree in advance to better and more efficiently allow for the desired notifications to be made. Note: As the caregiver, you also may want to include in this bag items that you may need (e.g., medications, snacks).
- If you are going to a specific location, e.g., on vacation, you may want to identify medical facilities in that area and, to the extent possible, check on their familiarity with PSC.
- For persons with severe fatigue, you can ask, in advance, for airlines to provide wheelchair assistance. Some airlines also provide front seating for persons with disabilities.
- The objective is to anticipate and identify potential issues before the event, to allow for smoother handling if such incidents should occur.

VIII. PSC and the Outside World

- For many PSCers, the expression “you can’t judge a book by its cover” is very applicable. Often, the PSCer’s outward appearance gives no indication of what is occurring on the inside: the scarring of the bile ducts, right upper quadrant pain, etc. In this way, the disease may be “invisible” to others, and its seriousness not understood. Caregivers in this situation can help by informing others about the disease. This can be done by providing pamphlets on the PSC Partners’ website (www.pscpartners.org/brochures) to interested persons when visiting the caregiver’s own doctors, etc.
- Because PSC is an invisible illness, too often friends and others may tell the person with PSC that he or she does not look sick, or that he or she looks great. While such statements may not be intended to cause harm, they can leave the PSCer with a feeling of not being believed. One helpful resource that can provide others with a better understanding of PSC’s impact is “The Spoon Theory”, found at www.butyoudontlooksick.com/the_spoon_theory.
- In a related context, each September there is a National Invisible Chronic Illness Awareness Week (see http://invisibleillnessweek.com/submit-article/30-things-meme/). The website lists 30 questions asking those with chronic illnesses to share with others what it is like to be invisible and ailing. From the website: “Even when we have known a person for decades there are still things we can discover about their daily life with chronic illness. And when we learn a bit more about what something is they love to hear, or what their morning may be like, it can help us be more compassionate to all of those around us who are suffering in ways we may not have noticed.” An interesting twist is for the 30 questions (or at least some of them) to be answered separately by the caregiver(s), as this could help the PSCer better understand the effect of their disease on others.

- There is no one common view on how much disclosure around the disease should be shared with the outside world. A determination on disclosure should be done in consultation with the PSCer; for younger PSCers, the caregiver needs to reflect on the possible impact from disclosures, both today and in the future. Here are a couple general questions that are good to consider. What is the purpose/objective for disclosure? What are the benefits and downsides to disclosure?
- Caregivers, the PSCer and their friends may want to run fundraisers both for the purpose of awareness and to raise research funds.

IX. Some Informational Sites

- Affordable Care Act (http://www.hhs.gov/healthcare/rights/index.html). This website provides information on the Affordable Care Act. Among the areas covered are Coverage, Costs, and Care. One important aspect of this statute for caregivers and people living with chronic illnesses is that individuals may no longer be denied health insurance coverage based on being diagnosed with a pre-existing condition.
- PSC Partners Seeking a Cure (www.pscpartners.org) is a mostly volunteer organization formed in 2005. It is a 501(c)3 nonprofit foundation whose mission is to provide education and support to PSC patients, families and caregivers and to raise funds to research causes, treatments and cures for primary sclerosing cholangitis.
- PSC Partners Seeking a Cure online support group for PSCers and caregivers to share social connection, education and experiences. There is both an open Facebook support group (open group - https://www.facebook.com/groups/39847120173/) and a closed Facebook support group (private group - https://www.facebook.com/groups/PSCPclosedgroup/).
- PSC Partners Patient Registry (www.pscpartnersregistry.org/). “The goal of the registry is to collect de-identified (anonymous) information on patients diagnosed with primary sclerosing cholangitis (PSC) in order to increase and accelerate research, enable clinical and drug trials, and find effective treatments for PSC.”
- Social Security Disability (http://www.ssa.gov/disability/) provides information on benefits for people with disabilities. Among the areas discussed are Social Security Disability Insurance (“pays benefits to you and certain members of your family if you are "insured," meaning that you worked long enough and paid Social Security taxes”) and Supplemental Security Income (“pays benefits based on financial need”).
- The Jennifer Jaff Center (http://www.thejenniferjaffcenter.org/), formerly Advocacy for Patients with Chronic Illness, was founded in March 2005, by attorney Jennifer C. Jaff. Its mission is “To provide free information, legal advice, education, and advocacy services to patients with chronic illnesses nationwide in areas including health and disability insurance, Social Security disability, employment discrimination, family and medical leave, educational equity, and resource location. In addition, to protect and promote the concerns of the chronically ill in public policy.”

*This document was prepared for the Saturday, April 25, 2015, PSC breakout session on “Caregivers: Helping Us Help Others” at the PSC Partners Annual Conference. The information, updated from the April 2014 document on the same topic, primarily comes from the PSC Partners Seeking a Cure website, the experiences of the panel members and from other caregivers and resources. The information in this document is not intended to, nor implied to be a substitute for professional medical advice, nor intended or implied to be used for medical diagnosis or treatment. As you review this document, please keep in mind that there is no one “playbook” for being a caregiver. Like you, we are still trying to learn. Valuable on-going resources for caregivers are the PSC online support groups (see above: IX. Some Informational Sites).