

Director's Report

The Patient-Doctor Relationship

Forgive me if I wax philosophical on a complex topic.

The Hippocratic Oath was once a central tenet of medical practice, emphasising the doctor's responsibilities to the patient in maintaining optimal care, compassion, and confidentiality. Modern medicine is complicated by the added interests and entities involved in health care provision, and now a number of stakeholders (society, government, public health services, consumer advocates,...) all have something to say, often with diametrically opposed preferences. A timely example is the recently-shelved Medicare GP co-payment, an initiative proposed by the government in an attempt to provide a "price signal" that might reign in the growing government costs associated with provision of a comprehensive health care system.

My approach to these conflicting imperatives is nicely summarised in the (utopian) words of Sapira: "The physician's purpose is not to classify patients into categories defined by numeric codes, to calculate quality-adjusted worthiness to live, to determine the allocation of a common pool of "resources", or to achieve bureaucratically determined societal goals and objectives." Rather, physicians place their knowledge and skills at the service of the patient for diagnosing and ameliorating (or healing) illness. Physicians practice medicine (from the Latin *medeor*, to heal).



While the doctor provides this role, the patient is not a passive spectator. To the contrary, the patient is the

active driver of the goals and processes involved in the therapeutic encounter. Patient responsibilities in the treatment encounter include – clear and accurate communication of their history and complaints; open discussion of their fears; and unambiguous expression of their expectations and hopes, as well as their treatment preferences. In response to the trust imbued in this honest communication, the physician must be respectful, compassionate, professionally competent, non-judgemental, honest, discrete, and skilled in communicating the proposed treatment plan.

The plan for management is not a "one-size-fits-all." There is no standard algorithm for managing a "typical" patient with lupus, for example. Rather, Mrs Smith may have skin and joint restricted lupus and express a desire to adopt "natural" medical therapies and so, after a discussion of the available options, it might be agreed that a symptom management and observational approach may be best. In contrast, Mrs Jones may have a very proactive biomedical approach to her lupus, and she may express a wish to embrace all available treatment options so, for her, a treatment trial of (say) hydroxychloroquine might be agreed upon, aiming to improve fatigue and mucosal dryness.



The word "contract" may sound dry and impersonal, but it conveys the flavour of an important aim for the treatment experience. A clear agreement should

be made, factoring in patient hopes, expectations, world-views and preferences, on the path forward, which will involve some combination of education, symptom management, life-style change, monitoring, medication and follow-up that differs from person to person.

With any long-term (chronic) health condition, it is important to ensure that both the doctor and the patient understand what the goals of treatment are – do we aim for alleviation of pain, improvement in energy, or return to part-time work, for example. What support systems need to be implemented to secure these goals? There may be a need for a chronic illness managed care plan, which can be coordinated by your primary care provider to allow rebatable assistance from paramedical colleagues (e.g. dietetic, psychological, exercise physiology, podiatry, dental).

The incorporation of *action plans* is also important for optimising patient quality of life and autonomy. This has been well defined for chronic conditions such as asthma, where symptoms and peak flow readings dictate patient-directed adjustment of therapy. A similar approach is often implemented for the management of fatigue, arthralgia, or intercurrent stressful events in the setting of autoimmune conditions such as lupus, Sjogren's and scleroderma.

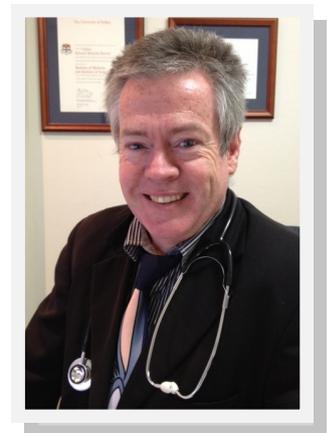
Last, but not least, everyone should consider advance care planning, regardless of their age and health – this planning process allows for reflection upon your priorities and preferences. Just as insurance involves preparation for things we'd rather not talk about, so, advance care planning involves the challenging thought process involved in imagining what you would prefer in the event that severe future illness precluded you from expressing your wishes at that time. This allows preferences to be written down, and may involve nominating a trusted person to make decisions in your interests if you were unable to do this for yourself at some time in the future.

The act of constructing advance care plans and directives does not imply that your current health condition is serious. Rather, it is a proactive step that can provide a welcome clarification of life priorities and preferences, whilst providing reassurance to the patient and their family by removing the mystery from this heretofore "taboo" topic. As Hannah Arendt said, "Prepare for the worst; expect the best; and take what comes."

Paternalistic medicine is, thankfully, a largely bygone practice. Current medical practice invests wisdom in the outcome of open clinical dialogue, rather than the commandments of an all-wise physician whose words must be followed like holy writ. As allies, the doctor and patient face a common challenge, working together to live with or (sometimes) overcome the patient's illness.

Best Wishes

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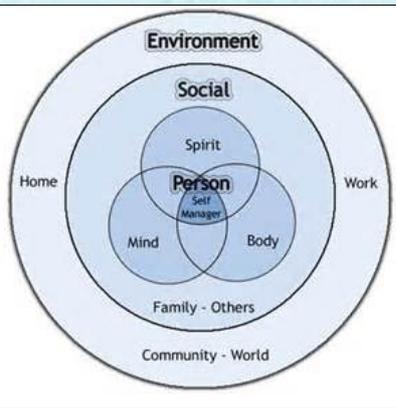
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Being an active self-manager: self-advocacy by communicating your needs



Being an advocate does involve being a foot soldier, meeting with the political power brokers and other community representatives and groups telling them about autoimmune illness and the need for better services and support.

ARRC as part of its advocacy role at every opportunity highlights current health service gaps and tries to at least have a voice helping to plan for the health future of our members. Aside from organisational involvement, advocacy can happen on a personal level. Learning how to be a self-advocate by being able to communicate your needs and life goals to family, friends and professionals involved in medically supporting you, is the first step in becoming an active self-manager. Effective communication of your health issues, needs and life goals is very important as poor communication can lead to poor relationships (health and personal), feelings of frustration, depression, anger and feelings of helplessness.

As a self-manager, it is best to learn the skills necessary to be an effective communicator. Learn language that put you at the forefront of advocating for your needs without conflict. It is important to give clear messages by being open and honest about your feelings, needs and aspirations. It is also important to learn to be an effective listener, allowing others to express their feelings. Learning to accommodate your illness by planning events, breaking large tasks into smaller manageable tasks, making short term as well as long term plans and also learning the art of compromise can all help. These skills can improve your quality of life by lessening the impact of having a chronic illness. Accommodating your illness and communicating what you can comfortably do and want to do will allow you to be an active life participant working with your illness symptoms and daily home, work and social schedules.

How would you ask for help? How would you say NO to doing something you don't want to or don't feel up to?

- Use "I" messages as "you" messages may suggest blame,
- Practise the use of words and statements such as "right now", "today", "at this point", "I am", "I feel"

Communicating your life goals and needs extends to all those around you and include your medical team. It is im-

portant to establish good communication with your doctors as it is likely to be a long-term one. Time is often the greatest deterrent to establishing a satisfying medical relationship which can lead to frustration, anxiety and misunderstandings for all. It may be helpful to plan out your next appointment by using the following strategies:

Think about the questions you want to ask and write them on a loose paper questions before hand. This paper can be given to the doctor or health professional at the end of the appointment and provides an opportunity for follow up.

- Be honest with the doctor and tell them of the symptoms that cause you the most distress and concern, as well as others. This can help prioritise treatment action plans.
- Ask about your diagnosis, tests, treatment options and risks. If you feel uncomfortable with your doctor and your treatment asking for a 2nd opinion is acceptable.
- Ask what extra things you can do to support the medical treatments suggested.
- Repeat key points back to the doctor, ask those "stupid" questions.

Be an active self-manager

- Write down instructions, admit if you do not intend to follow instructions
- Share the barriers you may have to the planned management treatment. These could be time, financial or even transport related if you live a long distance from treatment centres.
- Be honest with yourself and your doctor, don't be afraid to ask for explanations and tell them when you don't understand something. Often clarity comes with using simpler language or with the use of examples. "I don't understand, what do you mean?" is an important question when you are being an effective self-manager.

Being an advocate for your own health and your rights allows you to take back control at a time when the illness diagnosis, the numerous medical appointments and unpredictable illness symptom fluctuations may have called you to question your role.



Taking control by living well with illness is the goal. It is your life, your health so actively plan to be your own advocate.

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